



The Potential of ICT in supporting Domiciliary Care in England

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PREFACE

Launched in 2005 following the revised Lisbon Agenda, the policy framework ‘i2010: A European Information Society for Growth and Employment’ has clearly established digital inclusion as an EU strategic policy goal. Everybody living in Europe, especially disadvantaged people, should have the opportunity to use information and communication technologies (ICT) if they so wish and/or to benefit from ICT use by service providers, intermediaries and other agents addressing their needs. Building on this, the 2006 Riga Declaration on eInclusion¹ defined eInclusion as meaning “both inclusive ICT and the use of ICT to achieve wider inclusion objectives” and identified, as one of its six priorities, the promotion of cultural diversity in Europe by “improving the possibilities for economic and social participation and integration, creativity and entrepreneurship of immigrants and minorities by stimulating their participation in the information society.”

In the light of these goals, and given the dearth of empirical evidence on this topic, DG Information Society and Media, Unit H3 (eInclusion) asked the Institute for Prospective Technological Studies (IPTS)² to investigate from different angles the adoption and use of ICT by immigrants and ethnic minorities (henceforth IEM) in Europe and the related policy implications. In response to this request, IPTS carried out the study “The potential of ICT for the promotion of cultural diversity in the EU: the case of economic and social participation and integration of immigrants and ethnic minorities”, the results of which are available at the URL: <http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html>

In Summer 2008, as part of this research effort and following a pilot study performed a few months earlier in Italy, IPTS issued three tenders for parallel, linked studies to be conducted in Germany, Spain and the UK on the "The potential of ICT in supporting the provision of domiciliary care, with particular attention to the case of migrant care workers and informal carers". Given the widespread presence of migrant workers in both formal and informal long-term care services and also the growing diffusion of ICT-based tools and services in the provision of care in domiciliary settings, the studies aimed to broadly assess the current level of ICT diffusion in those settings and the current and potential support they provide to the diverse range of carers involved (paid and unpaid, with a recognised professional qualification/certificate or not), including those from a migration background.

This document is the final report on the research carried out between January and May 2009 in the U.K., specifically in England. The reports on the other three countries and a cross-analysis of main findings stemming from them are all available at the URL: <http://is.jrc.ec.europa.eu/pages/EAP/eInclusion.html>.

¹ Available at http://ec.europa.eu/information_society/events/ict_riga_2006/doc/declaration_riga.pdf

² IPTS is one of the seven research institutes of the European Commission’s Joint Research Centre

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EXECUTIVE SUMMARY

This study, carried out by CIRCLE (Centre for International Research on Care, Labour and Equalities, University of Leeds), is one of three linked studies³ commissioned by IPTS (Institute for Prospective Technological Studies), in order to explore available evidence and developments in ICT in supporting the provision of long-term care at home, paying particular attention to informal carers and immigrant care workers in Germany, Spain and the UK. The aims of the study were:

- To provide an overview of the size and organisation of domiciliary socio-health care provision in the UK, using existing data sources.
- To explore the role of ICT in supporting and enhancing the provision of care in domiciliary settings.
- To examine the way ICT is used by those receiving and delivering care in domiciliary settings.
- To examine the role of ICT in meeting the specific needs of IEM (immigrant and ethnic minority) carers/care workers.

Key informant interviews were conducted with representatives of selected organisations involved in social care and ICT developments, particularly those which employ immigrant care workers. A review of government policy and related strategies was also included. A case study methodology, involving a review of organisational websites, telephone interviews with key personnel and documentary analysis, was adopted for the main strand of the study. Eight organisations, each of which was already using ICT to address social care issues, provided information for the case studies.

Key findings

A summary of the key aspects of the social care system in England drew attention to the widespread nature of unpaid caring responsibilities, most of which are carried out by women and men of working age. It also indicated the still strongly feminised nature of the care worker population, which (in the UK) consists mainly of people employed by agencies and organisations, with some ethnic minority groups somewhat over-represented, but without the large numbers of migrant ‘grey labour’ seen in some other European economies. A trend towards concentrating publicly-funded services on those with ‘critical’ and ‘substantial’ needs, alongside new policy commitments to ‘personalisation’ and ‘cash-for-care’ systems, was highlighted.

A review of recent academic literature and national policy developments in the UK revealed that, although research in the use of ICT in social care is still in a rather early stage of development, there is already some evidence that technology of this type has significant potential to support carers (alleviating some of the pressures on them and helping them avoid some of the isolation they often face), and that it can be of benefit too to the large numbers of paid care workers who provide care to older, disabled or sick people in their own homes. A number of local authorities are already rolling out telecare services (ICT systems designed to help people live in their own homes) as part of their standard care provision packages. Nevertheless, other studies suggest that the new ICT-based developments becoming available are only just beginning to have a significant impact on the way existing health and social care services are provided and that this impact is currently uneven and unsystematic, with opportunities missed and some developments slow to make progress.

³ In fact, a preliminary exploratory study on Italy was also developed, but with a slightly different focus.

The eight case studies included in the study demonstrate the considerable potential and current limitations of ICT-based systems in the provision of social care, in relation to both service users and healthcare professionals. Some recently developed products, many of which had been introduced with considerable success and at relatively modest cost, included internet discussion forums, telephone help-lines, social networking and blogs, offering help and guidance and a means of communication to unpaid carers, and online training/resources and tools to assist in the professional lives and activities of paid care workers. However, many organisations did not have all the equipment they need to roll out these services to all staff and/or service users, and it was also felt that many people lacked the necessary skills or confidence to engage with such new ICT-based systems.

Additionally, the study showed that few organisations were providing services specifically geared towards IEM carers and/or care workers, finding that these were the exception rather than the rule. Only a handful were offering, to migrant or ethnic minority care workers or carers, services tailored to their particular needs, such as web-based advice and downloadable documents developed with their specific requirements in mind.

On the basis of this research, a number of cautious recommendations are proposed in relation to developing ICT-based services which will enhance service provision for both service users and healthcare professionals:

- Future research on the use of ICT in social care needs to involve all stakeholders, including service users and their carers, care workers, healthcare professionals, and the developers and suppliers of the different types of equipment.
- Effective awareness campaigns need to be developed without delay to promote the many ICT-based initiatives and solutions already being tested or put in place in the UK.
- Basic training schemes, highlighting the potential of technology in the social care system, and introducing a wider range of people to the equipment and technology available, would help overcome the lack of knowledge about available options and the benefits of new technology among carers and care workers alike.
- Online discussion forums have been shown in this study to be a very successful way of supporting carers in their caring role. These services, which can be put in place at comparatively low cost, establish a ‘virtual’ community of likeminded others engaging with similar care-based issues and able to offer each other support, and (potentially) sharing solutions to common problems.
- New research on the use of ICT in social care, geared specifically to the situation and circumstances of IEM carers and care workers, is urgently required.

Content of the report

In Part 1, the report presents a brief overview of the social care system in England, highlighting in particular evidence about, first, the unpaid carers (mostly family members, but sometimes friends or neighbours) and, second, the paid home care workers who support older, sick or disabled people, of all ages, in their own homes. In Part 2, we summarise a variety of ways in which ICT (including telecare) has begun to be used to support those involved in providing domiciliary care, highlighting both major publicly-funded initiatives and investments, and some of the approaches embraced by voluntary and private sector organisations. In Part 3, we present a number of concise case studies which illustrate the range of different ways in which these new developments are contributing to the support available to carers and care workers, including (in some of the examples) new approaches to supporting online dialogue and debate among carers. Part 4 addresses the particular focus

required for this study on immigrant and ethnic minority carers and care workers. This presents some evidence from the range of available statistical data on this topic (and notes the limitations of the available statistics). Our conclusions and recommendations based on the study, influenced also by the debate about the issues raised in the related German and Spanish studies,⁴ are presented in Part 5.

⁴ Discussed in a seminar in which representatives of all three studies took part, at IPTS in Seville, May 2009.

1. The social care system in England⁵

1.1 Introduction: key features of the English system

The current organisation of health and social care in England is based on:

(i) *Health care*

This is free at the point of use to all citizens (apart from dentistry and prescriptions), through the National Health Service, first established in 1948. Free health services include hospital consultations and treatment (including both elective and emergency procedures) and primary health care, including GP (general practitioner) services and community health services (including community nursing care). For each user of the NHS (except in emergencies) GPs act as the gateway to hospital and to any consultations with hospital doctors and consultants.

Healthcare is funded via the Department of Health, which allocates budgets (derived from general taxation) to NHS Trusts, Primary Care Trusts and other relevant agencies.⁶

(ii) *Social care*

In the English system, this is defined to *exclude* nursing care, but to *include* personal care, including that needed by people with long-term conditions and disabilities. In England, social care is the statutory responsibility of 150 local authorities, referred to as CSSRs - 'councils with social services responsibilities'. Currently, each of these authorities must discharge its responsibilities through separate arrangements for Adults' and Children's services. Social care is paid for with resources made available to local authorities by central government (using funds derived from general taxation) and from the additional resources which local authorities raise directly via local taxation or through charges to service users.⁷ All local authorities are required to levy local taxes based on property values, known as Council Tax. They have some control over the level at which these taxes are set, and Council Tax rates are considerably higher in some localities than in others.

Under law, local authorities must arrange social care services for eligible clients, although (since the late 1980s) they have been discouraged from providing all of these services directly via their own employees. Indeed, under the *NHS & Community Care Act 1990* they are required to operate a 'mixed economy' of care, which must include purchasing some services from the independent sector. The services affected by this legislation include home (domiciliary) care and residential care for eligible older and disabled people.

To establish their eligibility for, and entitlement to, social care services (including day care services, home care services and residential care), adults who are sick, disabled, frail or vulnerable must have their care needs assessed by a qualified social worker, who is usually a local authority employee.⁸ Currently, the social worker completing the assessment will decide whether the person seeking social care support has care needs which can be classified as

⁵ In some sections of this report we draw on our previous work in related fields. Where previously published material is referred to, the sources we have used are cited in the references given at the end of the report.

⁶ Many NHS hospital doctors also engage in private practice and, particularly for routine surgery and procedures, some patients with private health insurance or the means to pay for private treatment choose this option.

⁷ The *Commission for Social Care Inspection* (CSCI) estimates that local authorities raised £1.78 billion from charges for services delivered to older people receiving local-authority supported care in 2005-06, and notes that some of these people 'also topped up care packages to the tune of an estimated £0.58 billion' (CSCI, 2008: 115).

⁸ As indicated later in the report, unpaid family carers (hereafter 'carers') of eligible persons also have the right to have their own needs assessed, under legislation passed in 2000.

‘critical’, ‘substantial’, ‘moderate’ or ‘low’. In making this judgment they must (since 2003) have regard to national policy guidelines on *Fair Access to Care Services* (FACS). However, CSSRs in England may make their own decisions about the level of need which has to be established before adult social care services will be provided. As a result of this discretionary aspect within the social care system, there is no single FACS level of need triggering eligibility for service provision in England. In 2007/8, four CSSRs restricted the provision of their social care services only to clients whose needs were assessed as ‘critical’; a further 106 CSSRs restricted provision to those whose needs were assessed as either ‘substantial’ or ‘critical’. This left about 40 CSSRs supplying services to clients with moderate or low levels of need. Noting that ‘in 2007-08 some 73% of councils plan to operate only at the highest two levels, compared to 58% of councils in 2005-06’, CSCI⁹ (the Commission for Social Care Inspection) commented:

The setting of thresholds and targeting of resources has had a significant effect on the level of non-residential services provided by councils, and particularly home care services. Since 1997, the numbers of households receiving supported home care has fallen from 479,000 to 358,000 in 2006. At the same time, the total number of hours of care has increased from 2.6 million to 3.7 million; the average hours per household in 2006 was 10.8 hours, double the 1997 figure.

(CSCI, 2008:118)

In addition, local authorities normally apply a ‘means test’ to those assessed as in need of home care services, to determine whether or not they will be expected to contribute to the costs of the services required.¹⁰ Different rules apply in relation to residential and other care. In the case of non-residential services for adults, as CSCI explains:

Councils can decide how much to charge people (whose care needs meet eligibility criteria) for non-residential care. National guidance puts limits on the maximum that councils can charge people on low incomes but councils are free to reduce charges should they wish. Indeed, councils can decide to waive charges entirely, thus removing a means test, although this is rare. By contrast, for people with income and savings above the relevant minimum, councils can charge up to the full cost of care. So even where people are eligible on the basis of need and choose to opt for council-supported care, in most cases people are potentially required to make some form of contribution from their own pockets.

(CSCI, 2008: 112)

This discretionary arrangement thus introduces a further element of local variability within England.¹¹ In total, CSSRs recovered over £2 billion in fees and charges for services in 2005-06 (14% of total gross adult care expenditure). While 79% of this income was for residential and nursing care, charges for home care services also accounted for a significant sum - £246m, or 12% of total income from fees and charges (CSCI 2008: 8).

Overall, CSCI estimates that ‘just over 600,000 older people were using council-supported community-based services (in March 2006). A quarter of these people paid a charge to their council towards the cost of this care.’ A further 150,000 older people are estimated to have been ineligible for council-supported care, but purchasing care at home privately (self-funders). CSCI considers that about a quarter of those in receipt of council-funded

⁹ On 1 April 2009, the work of CSCI moved into a new *Care Quality Commission*.

¹⁰ Some CSSRs will only pay for home care services for those who have savings of less than £21,500 – the threshold figure above which they charge users for residential care. Current arrangements for providing financial support to those requiring residential care (excluding nursing care) are described in more detail by CSCI in its report, *The State of Social Care in England, 2006-7*, Part 2 (CSCI, 2008).

¹¹ Because health and social care are ‘devolved’ areas of responsibility, in Wales, Scotland and Northern Ireland different arrangements apply. Some of the key differences as they affect carers in England, Scotland and Wales were summarised in Section 1 of Yeandle et al (2007).

community-based care ‘top up’ their care package privately, and that (in total) ‘about 40% of people pay for some care privately’. (CSCI 2008: 113).

Despite this rather complex situation with regard to the funding of home care and other services, and the significant local variability it implies, CSSRs have been strongly encouraged over the past 10-15 years to support people to remain at home wherever possible; so much so that admission to residential care is now widely regarded as an arrangement of last resort. Under the *Community Care (Delayed Discharges, etc) Act 2003*, they are also penalised if, by failing to put in place suitable ‘packages’ of social care, they delay hospital discharge (sometimes referred to as ‘bed blocking’).¹²

Local authorities are also obliged to put in place suitable home adaptations where there is a risk to a sick, disabled, frail or vulnerable person’s personal safety in the home. Almost all local authorities also have in place some kind of warning/danger alert systems (usually referred to as Community Alarm Systems – CAS), enabling people who live alone to summon help in an emergency (for example if they suffer a fall); local uptake of these schemes, and expenditure on them is variable. As described below, some form of telecare, beyond basic community alarms, is also available in many English local authorities, but so far the resources allocated to telecare have been relatively modest (see below), target numbers for households supported by telecare are small (relative to the total number of home care users) and there is significant variation between local authorities.

1.2 A new emphasis on the provision of care in English social policy

Change and reform in the English system of social care

For the past decade, demographic and social change, and a strong voluntary sector lobby on carers’ issues¹³ has been pushing social care and the provision of care (whether paid or unpaid) up the policy agenda in both social and employment policy in Great Britain. Government has recognised the importance of these change pressures (and that they are set to continue), and has begun to respond actively to population ageing, aware that over the first 25 years of the 21st century, the country is likely to need both 2 million more workers and 3 million more carers. In England, the numbers of people aged 75+ are expected to increase by over 52% between 2005 and 2025, and of those aged 85+ by almost 75% (Table 1).

¹² Audit Commission (2004).

¹³ With the support of an All-party Parliamentary Group on carers and academic /third sector research on carers.

Table 1: Population Projections 2005- 2025			
2005	England	Wales	Scotland
All	50,434,445	2,964,057	5,097,084
Aged 75+	3,866,188	249,502	376,942
Aged 85+	995,533	62,943	90,627
Percentage of whole population aged 75+	7.7	8.4	7.4
Percentage of whole population aged 85+	2.0	2.1	1.8
2025			
All	55,594,202	3,209,556	5,114,403
Aged 75+	5,888,391	387,494	582,851
Aged 85+	1,739,151	110,091	171,984
Percentage of whole population aged 75+	10.6	12.1	11.4
Percentage of whole population aged 85+	3.1	3.4	3.4
Change 2005-2025			
All	5,159,757	245,499	17,319
Aged 75+	2,022,203	137,992	205,909
Aged 85+	743,618	47,148	81,357
All (% change)	10.2	8.3	0.3
75+ (% change)	52.3	55.3	54.6
85+ (% change)	74.7	74.9	89.8

Source: 2004-based national population projections, Government Actuary's Department, Crown Copyright

National policymakers have also noted that, thanks to better healthcare, many sick and disabled people, including babies and children with serious illnesses and disabilities, are also living longer. Those who experience serious illness, or require hospital care, are increasingly affected by policies on earlier discharge and the possibility of receiving treatments in the home environment. A wide range of conditions are now being managed outside of hospital or residential care, increasingly with the support of telecare and telehealth interventions, and this too implies that more care, provided by unpaid carers or by paid domiciliary care workers, will be needed in home settings.¹⁴ This raises critical issues for local authorities and others with responsibility for arranging, providing and delivering care services and support. A key current policy issue, currently unresolved, is that this development produces savings in expenditure on health provision, but some additional costs in the social care system. These are separately funded in the English system, and there is currently no agreed mechanism for resourcing these additional social care costs from health cost savings.

The relevance of technological change and of new forms of ICT for the health and social care sector – seen as potentially representing sustained ‘productivity gains’ in the health and social care sector (gains macroeconomists expect to continue [Wilson et al, 2008]) - can hardly be under-estimated. More care at home, for more people, with more complex needs (being supported outside of hospital and residential settings) requires significant support, either from domiciliary health and social care staff, from unpaid carers, or, very often from a combination of both. In introducing national programmes of investment in telecare and related developments (see below) the British government has indicated the significance it attaches to these developments, which it hopes will deliver both savings and service enhancements. ICT developments are seen as offering scope for: (i) improved communication between carers, those they care for, and health and social care professionals; (ii) greater independence, dignity, choice and control for sick and disabled people; and (iii) more reliable monitoring,

¹⁴ Telehealth developments are gaining pace and may have a major impact on this situation. Three ‘Whole Systems Demonstrator’ projects are currently being tested alongside telecare (see also later in the report).

risk management, and more effective warnings and alerts, especially where sick and disabled people live alone or have conditions requiring regular checks, management or supervision. These aspects and the available evidence base are discussed in more detail in Part 2 of this report.

Alongside the major demographic developments mentioned above, macroeconomic labour market projections show Britain continuing to need more skilled and experienced labour, while its 'working age' population is shrinking – the combined effect of extended education, smaller cohorts of young people starting work, and early withdrawal from the workforce (Carone, 2005; European Commission, 2006). The most recent estimates suggest 2 million additional jobs will be created in the UK between 2007 and 2017 alone, with much of the additional demand for labour in skilled and higher level occupations, including some 400,000 posts in health and social work occupations (Wilson et al, 2008). The 40-plus age group, where most caring occurs, will continue to include many men and women in whom the state and employers have made expensive training investments – and on whom employers, managers and co-workers rely for their experience, organisational knowledge and maturity. Among unpaid carers of working age, almost 2.2 million in the UK combine their care with other, paid, work, some 1.5 million of them in full-time jobs, and the remainder in part-time employment (Buckner and Yeandle, 2006). These carers often report significant stress and strain, which ICT investments can in some circumstances alleviate, since among the pressures they report are difficulties in communication with those cared for, and the need for peace of mind from anxieties about the person cared for and their ability to manage their own condition (Carers UK, 2007). As both men and women commonly combine work and care (about 43% of all carers of working age are men), and unpaid carers are distributed fairly evenly across most industrial sectors and occupational groups, responding to increased demands for care will affect employers and organisations across all segments of the labour market.

Throughout the past decade, it has become government policy in Britain to encourage and support the development of a new vision for the national social care system, emphasising independence and choice for individuals who need care and support, calling for arrangements which accord dignity and respect to disabled people, those using health and social care services and their (unpaid) carers, and arguing for a more integrated health and social care system capable of tailoring support and services to the needs of individuals and their families. Box 1 summarises some of the key recent developments highlighted by government in official policy documentation. The challenges posed for the social care system, and particularly for recruiting, developing and retaining sufficient numbers of suitable domiciliary care staff, are recognised by local authorities throughout the country (Yeandle, Shipton and Buckner, 2006).

In May 2008, the government published a consultation document designed to stimulate national debate about new system requirements for social care: *'The case for change - why England needs a new care and support system'* (with the strap-line 'Care, support, independence: meeting the needs of a changing society'). This consultation closed in November 2008, and is to be followed by a new Green Paper on the 'future shape of the care and support system', which the UK government plans to publish in June 2009.¹⁵

¹⁵ This date was announced in the April 2009 Budget Report.

Box 1: Social Care Reform in England (2007- 09)

The Department of Health works to define policy and guidance for delivering a social care system that provides care equally for all, whilst enabling people to retain their independence, control and dignity. The framework for cross sector reform is set out in Putting People First: A shared vision and commitment to the transformation of Adult Social Care, the Ministerial Concordat launched on 10 December 2007.

<p style="text-align: center;">Putting People First <i>a shared vision and commitment to the transformation of adult social care</i> 10/12/2007</p> <p>This established the collaboration between central and local Government, the sector's professional leadership, providers and the regulator (10/12/07). It sets out the shared aims and values which will guide the transformation of adult social care, and recognises that the sector will work across agendas with users and carers to transform people's experience of local support and services.</p>	<p style="text-align: center;">Personalisation</p> <p>Across Government, the shared ambition is to put people first through a radical reform of public services. It will mean that people are able to live their own lives as they wish, confident that services are of high quality, are safe and promote their own individual needs for independence, well-being and dignity.</p>
<p style="text-align: center;">Dignity in Care</p> <p>The aim of the Dignity in Care campaign is to eliminate tolerance of indignity through raising awareness of the issues and inspiring people to take immediate action.</p>	<p style="text-align: center;">Transforming social care Local Authority Circular, 17/01/2008</p> <p>Information to support the transformation of social care, including a copy of the Social Care Reform Grant Determination, and details of the new ring-fenced grant to help councils to redesign and reshape their systems over the next 3 years.</p>
<p style="text-align: center;">Independent living</p> <p>Enabling disabled people to fulfill the roles and responsibilities of citizenship from youth through to old age, while supporting their dignity, independence and choice.</p>	
<p>Care services efficiency delivery <i>Supporting the implementation of independent recommendations to improve public sector efficiency.</i></p> <p>The Department of Health established the Care Services Efficiency Delivery programme (CSED) in June 2004. The aim of CSED is to support the implementation, of the recommendations of an independent review of public sector efficiency, which was led by Sir Peter Gershon. The programme works collaboratively with local councils, the NHS and service providers, in order to develop and support initiatives which provide sustainable efficiency improvements in adult social care. CSED has a target to assist councils to deliver £684 million in efficiency improvements in 2007 and 2008. There are six workstreams for efficiency improvement, focused on:</p> <ul style="list-style-type: none"> ▪ <i>effective monitoring and modernisation of home-based care</i> ▪ <i>assessment and care management</i> ▪ <i>demand forecasting and capacity planning</i> ▪ <i>homecare re-enablement</i> ▪ <i>improved procurement practices</i> ▪ <i>transforming community equipment and wheelchair services.</i> <p>The programme is now being rolled-out through a regional strategy. Bringing the benefits of its work streams, initiatives and products to all nine Association of Directors of Adult Social Services regions, covering all 150 CSSRs in England.</p> <p style="text-align: center;"><i>(Text in Box 1 adapted from official Department of Health website, accessed February 2009)</i></p>	

Direct payments

Key aspects of strategic developments in social care over the past 15 years include the introduction of Direct Payments, a form of cash for care scheme (see Yeandle and Stiell, 2007, for a detailed description of the scheme, its origins and early implementation), initially for sick or disabled people under state pension age only. This was legislated for in the *Community Care and Direct Payments Act 1996*. From 2000 (under the *Community Care (Direct Payments) Amendment Regulations, 2000*) the Direct Payments scheme was also made available to older people (aged 65 and older). It was subsequently further extended (in 2001) to include carers, parents of disabled children and 16 and 17 year olds. The total number of people receiving Direct Payments, initially very small, has been rising - from 37,000 in 2005-6 to 67,000 in 2007-8 (in England). This represented 2.48% of all clients receiving community-based services in 2005-6, and 4.36% in 2007-8. Among people aged 75 years or older, 15,000 (2.87% of all clients of this age) received Direct Payments in 2007-8.

Direct Payments put those cared for in control of the funding available to support them; many users of Direct Payments employ their own personal assistants and care workers. The figures for take-up nevertheless indicate that, despite considerable emphasis on the development of this policy, the proportion of clients, including older clients, currently using Direct Payments remains extremely small relative to the total population of service users (HSCIC, 2008).

Service use and uptake

In this context, it is also important to note that, in England, only about 1 in 8 people aged 75+ is a client of any type of community-based service arranged by statutory social services, and that only a very small minority of older citizens, about 6% according to the latest available figures, are users of publicly funded home care services. Clearly this in part reflects the relatively strict eligibility criteria applied by most CSSRs, as discussed above.

Nevertheless, compared with uptake of Direct Payments, a much higher proportion of clients receiving community based services are users of *home care services*. These services were provided to 577,000 clients in 2007-8, of whom 82% were people aged 65 or older.

In a further development, Individual Budgets (IBs) now also form part of the Government's 'modernising' social care agenda. These are expected to be important in delivering the 'personalisation' agenda (see Box 1) in the future. First proposed in a government report, *Improving the Life Chances of Disabled People* (Cabinet Office Strategy Unit, 2005), IBs have been piloted for both disabled and older people. Thirteen local-authority-led IB pilot projects ran in 2005-7 and have been evaluated (Glendinning et al, 2008). They were designed to build on both Direct Payments and on the earlier *In Control* projects (developed for people with learning disabilities). Their key principles were: service users should play a greater role in the assessment of their needs; individuals should know the level of resources available to them before starting to plan how they would like their support needs to be met; IBs would integrate resources from different funding streams; assessment processes and eligibility criteria should be simplified, with adult social care as the gateway; individuals should be encouraged to identify the outcomes they wished to achieve, with support in planning how to use their IBs, including information on the costs / availability of different options; IBs could be spent on existing services, including commercial services or to pay relatives and friends for the help they provide.

The Commission for Social Care Inspection (see below) reported that '*nearly 4,800 people had an Individual Budget at March 2008, with just under half having a Direct Payment as part of the arrangement. The average annual gross value of an Individual Budget has been estimated as £11,450 – most of which is social care funding*'. (CSCI, 2008)

Home adaptations

Specific funding is also available to provide home adaptations/equipment. Equipment and adaptations were provided to 519,000 home-based clients in 2007-8, of whom 400,000 (77%) were aged 65 or older (compared with 499,000 in 2005-6, of whom 387,000, also 77% were aged 65+) (Health and Social Care Information Centre, 2009). Unfortunately, the data available do not at present distinguish between those provided with physical adaptations to their homes (grab-rails, lifts, ramps, bathroom equipment, etc.), wheelchairs and other mobility aids, and ICT enabled adaptations.¹⁶

Telecare

As indicated in more detail in Part 2 of this report, a major national initiative to introduce telecare across England was introduced by central government, via a funding stream made available by the Department of Health, in 2006. This initiative forms a relatively small but important element of overall public policy on health and social care (and has been mirrored in other parts of the UK). While it would be premature, just five years later, to describe this as, at present, a main feature of current health and social care arrangements, it is evident that telecare and telehealth are likely to be key components of the system of care and support in England going forward. What is unknown at present is whether these developments will be accelerated and supported by national policy and investments, or will continue to develop at an uneven pace, with the scale and scope of developments very different (as now) in different CSSRs.

Expenditure on personal social services

An overview of recent spending on the personal social services in England is provided in an official publication of the Health and Social Care Information Centre, part of the Department of Health (England). Box 2 cites its most recent summary statement on this topic.

¹⁶ However a recent study of the satisfaction of home-based clients receiving 'community equipment and minor adaptations' is available, Health and Social Care Information Centre (2008).

Box 2: Personal Social Services Expenditure and Unit Costs: England 2007-08

- Gross current expenditure by Councils with Social Services Responsibilities in England on Personal Social Services was £20.7 billion. This represents an increase of 3 per cent in cash terms since 2006/07 but little change in real terms. Over a longer term, this represents a real term increase of 11 per cent since 2003-04 and 53 per cent over the 10 years from 1998-99.
- Of the £20.7 billion, expenditure on Adults services accounted for £15.3 billion, similar in real terms to 2006-07; the remaining £5.4 billion was spent on Children's and Families services which represents an increase of 1 per cent since 2006-07 in real terms.
- Expenditure on residential provision for all client groups accounted for 41 per cent and day and domiciliary provision for all client groups accounted for 43 per cent of total gross current expenditure, whilst assessment and care management accounted for 16 per cent.
- Expenditure on services for children and families accounted for 26 per cent of total gross current expenditure, whilst expenditure on services for older people accounted for 42 per cent. Of the remaining expenditure, 17 per cent was on services for learning disabled adults, 7 per cent on physically disabled adults, 5 per cent on adults with mental health needs and 2 per cent on services for other adults, asylum seekers or service strategy.
- The average cost per adult aged 18 and over supported in residential care, nursing care or intensively in their own home was £559 per person per week.
- The expenditure on Direct Payments for adults was £452 million. This is an increase of 28 per cent in real terms from 2006/07 and nearly five times the figure in 2003/04 in real terms (although from a very small base). The percentage of gross expenditure used for direct payments for adults equates to 2 per cent of the overall gross current expenditure in 2007-08.

Quoted from Personal Social Services Expenditure and Unit Costs England, 2007-08, HSCIC, 2009b

Home care

Most paid home care workers are employed by local authorities or by independent sector agencies. The General Social Care Council (GSCC)¹⁷ regulates the social care workforce and from 2002 has published codes of practice for social care workers. In 2008, it noted:

The GSCC today welcomed the launch of the National Skills Academy for Social Care, saying that employers must make the provision of training for their workers 'a priority'. The GSCC currently regulates social workers and will register other social care workers over time, starting next with home care workers and managers Regular training and development will be a key part of registration with the GSCC when we begin to open the register to other parts of the workforce. Providing training opportunities for workers should be a priority for any social care employer and we (will work) with the Skills Academy towards making this a reality.

Skills for Care is the employer-led authority on the training standards and development needs of social care staff in England. It provides over £25 million in funding to support improved training and qualifications for managers and staff, working with social care employers and training providers to establish standards and qualifications (see Box 3).

¹⁷ The GSCC is a Non Departmental Public Body established in October 2001 under the *Care Standards Act 2000*. It is sponsored by the Department of Health but also works closely with the Department for Children, Schools and Families in delivering the children's and young people's care agenda.

Box 3: New Care Skillsbase website launched to support care workers

Free online communication and number skills website **Care Skillsbase** was launched this week at the Skills for Care national conference. Care Skillsbase is a partnership between Skills for Care and the Social Care Institute for Excellence and is designed to help 38,000 social care employers assess and improve the communication and number skills of 1.5 million care workers. At the click of a button managers can identify what skills their workers need to be able to effectively support people who use services and carers. The online resource includes a comprehensive Skills Check, a Manage Skills section and a Compare Standards facility allowing managers to check their understanding of safety and quality including the Common Induction Standards, NVQs and GSCC Codes of Practice.

"Care Skillsbase has been piloted with employers who told us that they wanted support to develop the communication and numbers skills of their workers so they can communicate more effectively with the people they work with," says Skills for Care CEO Andrea Rowe. "Our own research suggests that there are significant communication and number skills gaps right across our sector and this easy to use website will go some way to helping us address them in a sensitive and practical way. This online resource helps managers to discuss skill issues constructively with staff in a non-threatening way and also provides evidence for use in inspection in relation to staff development."

Care Skillsbase can be accessed free of charge at www.scie-careskillsbase.org.uk

Skills for Care News release - 26 February 2009, Ref 05/09

In April 2009, the government announced a 'New Strategy for a 21st century social care workforce'. This will include *CareFirst* – a scheme to support 50,000 long-term unemployed people to access employment in social care; an additional 1,300 apprenticeships in social care; a new Management Trainee Scheme to encourage graduates and 'top quality executives' to enter the sector; and a new voluntary registration scheme for home care workers. Introducing the scheme, the Care Services Minister stated: '*this new Strategy will help to raise the status of social care careers*'.

The emergence of carers' rights

In the past forty years, third sector carers' organisations have lobbied to secure for (unpaid) carers a range of new rights, entitlements and policies. Underpinning their approach has been a belief that carers are a group entitled to equal opportunities and human rights – to be treated with dignity and respect; to be able to access education, training and employment; to have a life outside caring; and to enjoy freedom from caring 'penalties' – in terms of poor health, poverty, social isolation and social exclusion. To date, certain new rights have been accorded to carers, although they are not currently treated as a distinct group whose rights are protected under all equality legislation. These new rights include: the right to unpaid leave from work to deal with emergencies and caring crises; the right to request flexible working arrangements; the right to a Carer's Assessment (which acknowledges their desire to work as well as to care); and the right to access education, training and employment (Box 3). The incoming Labour Government set out its position on carers in an initial National Carers' Strategy in 1999. This played a key role in raising the profile of carers, although it was not accompanied by major programmes of investment. Among other things, it introduced a special Carers Grant for CSSRs (which has influenced local developments – see Fry, Price & Yeandle, 2009), and identified telecare as relevant to carers' situation and a mechanism through which some carers could be supported. Government laid out its revised 'vision' for carers, in the development of which voluntary agencies had a strong voice, in June 2008, in *Carers at the Heart of 21st Century Families and Communities* (see Box 4).

Box 4: Revised National Carers Strategy - June 2008

Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own

The official website of the Department of Health provides a link to the full strategy, which it summarises as follows:

- The carers' strategy sets out the Government's short-term agenda and long-term vision for the future care and support of carers
- The carers' strategy is underpinned by £255 million to implement some immediate steps alongside with medium and long-term plans.
- New commitments in the carers' strategy include: £150 million towards planned short breaks for carers; £38 million towards supporting carers to enter or re-enter the job market and £6 million towards improving support for young carers. Other schemes include the piloting of annual health checks for carers to help them stay well and training for GPs to recognise and support carers. A more integrated and personalised support service for carers will be offered through easily accessible information, targeted training for key professionals to support carers, and pilots to examine how the NHS can better support carers.

HM Government, 2008

Carers' new rights and entitlements, and the government's new vision for carer support, form the backdrop to the activities of local agencies with statutory responsibilities. The new legislation affecting carers (see Box 5) has, for the most part, had all-party support; and policy-makers and social care professionals have mostly welcomed the shift towards a more explicit focus on carers' circumstances. Some employers' representative organisations also now welcome and support the limited new rights carers now enjoy in the workplace. The carers' lobby continues to call for stronger policies, much more public investment in the services which support carers, and heightened employer and managerial awareness of carers' needs, noting that these valuable changes and developments are very far from an adequate response, given the scale and range of carers' needs. In general, these agencies have been keen to encourage the use of ICT and telecare as a means of enhancing support for carers and those they care for. Box 5 summarises policy developments in different areas of health and social care as they have affected carers since 1995.

Box 5: Main legislative and policy developments in England affecting unpaid carers

Date	Development	Key change for carers*
1995	<i>Carers (Recognition and Services) Act</i>	Introduced the concept of a carer's assessment.
1999	<i>Caring About Carers: a national strategy for carers</i>	Stressed that enabling carers to combine paid work and care was a priority for government.
1999	<i>Employment Relations Act</i>	Gave employees the right to 'reasonable time off' to deal with emergencies.
2000	<i>Carers and Disabled Children Act</i>	Gave carers the right to an assessment for carers of adults and people with parental responsibility for disabled children. Allowed carers to receive services in their own right. Enabled local authorities to give direct payments to carers for their own services and or to parents of disabled children to manage on their children's behalf.
2000	<i>Changes to Invalid Care Allowance (now known as Carer's Allowance)</i>	Amendment to the Social Security Contributions and Benefits Act 1992, which included extending carers' benefits to people aged 65 and over.
2002	<i>Employment Act</i>	Gave employed parents of disabled children under the age of 18 the right to request flexible working arrangements
2004	<i>Children Act</i>	Requires local authorities to lead on integrated delivery through multi-agency children's trusts and to develop a children and young people's plan. The Act includes a strong policy emphasis on supporting families and carers, described as 'the most critical influence on children's lives'.
2004	<i>Carers (Equal Opportunities) Act</i>	Placed a statutory duty on social services departments to inform carers of their rights, and to consider carers' wishes in relation to education, training and employment when conducting carers assessments
2004	<i>Every Child Matters: change for children</i> <i>Policy document</i>	Indicates that disabled children and children with long term health conditions should 'receive co-ordinated services which allow them and their families to live as ordinary lives as possible.' 2007, UK government has announced £340m (2008-2011) for services for disabled children in England - £280m is for short breaks for families with children with severe disabilities
2006	<i>Work and Families Act</i>	Extended the right to request flexible working arrangements to all carers in employment, from April 2007.
2006	<i>Childcare Act</i>	Contains provisions relating to the 'duty to provide sufficient childcare for working parents'; and requires local authorities to 'have regard to the needs of parents' for 'provision of childcare suitable for disabled children'.
2007	<i>New Deal for Carers</i> <i>Policy announcement</i>	Package of measures relating to respite, emergency planning, help-lines and training for carers.
2007	<i>Pensions Act</i>	Recognises carers' situation: reduces the number of qualifying years needed for a full basic State Pension; replaces Home Responsibilities Protection with weekly credits; introduces a new carers' credit for those caring 20+ hours a week for someone who is severely disabled.
2008	<i>Carers at the Heart of 21st Century Families and Communities</i> <i>Revised National Carers' Strategy</i>	Sets out a 10-year 'vision' for a support system for carers that is 'fit for the 21 st century'. Commitments made in relation to: information and advice; breaks for carers; better NHS support for carers; employment support for carers; protection from inappropriate caring roles for young carers; training for carers; training for professionals in contact with carers; improvements to information about carers. Identifies as key priorities: the 'personalisation agenda', easy to access support, reform of carers' benefits, development of best practice models based on quality / innovation, expanded NHS services, arrangements for Carers Grant and clarification of mechanisms to ensuring carers can access appropriate information, especially in cases where mental capacity is an issue.

Some aspects of these recent changes have moved beyond ‘enabling’ legislation and policies, and given to carers limited but enforceable rights, placing new statutory obligations on local authorities, employers and others. However, delivering new forms of support for carers has been held back by resource constraints, organisational inertia and blockages, and sometimes by out-of-date attitudes towards carers, or ignorance of the ubiquity, importance and necessity of carers’ roles. The importance of good quality relationships, effective communication and a reliable division of labour between carers and care workers, developed in active consultation with those cared for, enabling sick or disabled persons to have the independence, control and choice now accepted as their right, is beginning to be widely understood. The official *State of Social Care* annual reports, published in relation to the system in England (since 2005), have been an important mechanism for drawing attention to these linkages, and for highlighting the need for change and to embrace new technology as a means of achieving this goal (CSCI, 2005, 2006, 2007, 2008, 2009).

At present, only a minority of carers with significant caring roles have had their own needs assessed (an option to which they are legally entitled, see Box 5), and it is widely recognised that the quality of the assessment process and its outcomes can be highly variable. Some local authorities have been innovative, resourceful and imaginative in developing new support for carers, engaging carers directly in the process of modernising the services they offer – but these examples of excellence are far from the universal situation. New developments recently put in place in some localities include a range of telecare and ICT solutions, often introduced as pilot projects or experimental innovations; some of these projects and schemes are outlined and discussed later in the report.

Resources allocated to supporting carers

‘Carers’ Special Grant’ was first introduced in England in April 1999 as an additional financial allocation to all local authorities, and is now known as ‘Carers Grant’. The overall allocation was stabilised at £185 million for 2006/7 and 2007/8, having been increased by £60m to £185m in 2005/6.¹⁸ [Since late 2003, Carers Grant has ceased to be a ring-fenced allocation, although guidance is still issued to local authorities on the government’s policy intentions in allocating this funding.] In 2005/6 the government’s official guidance indicated that Carers Grant was intended to help local authorities to further develop innovative, high quality carers’ services including:

- Develop high quality, flexible and innovative services.
- Create pragmatic and outcome-focused approaches to Carers Assessment, and encourage joint working with local health services.
- Focus on the needs of carers, considering their well-being, and develop services to address carers’ skills and build their confidence.
- Provide breaks to those who care for a relevant adult.
- Provide breaks and services for disabled children and their families.
- Provide breaks and services to children and young people who are carers.
- Fund the administration of Carers Grant activity.
- Develop local priorities with local stakeholders and formulate a plan for Carers Grant activity.

¹⁸ Carers’ Grant does not represent all spending on services which support carers. Services to users, funded out of local authorities’ Adults’ Services / Children’s Services core budgets, are also important in supporting carers.

- Implement the provisions of the *Carers (Equal Opportunities) Act 2004* by giving more choice of services, providing relevant information and taking account of carers' wishes regarding leisure, training, education and employment in the carrying out Carers Assessments.

Emphasis was placed on better consultation processes with carers and stakeholders about the strategic planning of services and about how the Carers Grant would be spent locally. Funded activity was meant to advance the provisions of the *Carers (Equal Opportunities) Act 2004*. In 2005/06 the Commission for Social Care Inspection's (CSCI) assessment of adult social care performance¹⁹ noted that 9% of carers were receiving specific carers' services.²⁰

Carers' assessments and the provision of home care services

Those who provide 'regular and substantial care' to a sick, disabled, or older person are now entitled to have their own needs assessed (by their local authority social services) if they wish. Local authorities have a statutory responsibility (see Box 5) to offer such an assessment in appropriate cases (and must record if their offer is declined) and to arrange suitable support where it is needed. Tables 2 and 3 provide official data on these assessments, which are intended to be quite independent of the assessment of the needs of the person(s) the carer cares for. As shown in Table 2, only a minority of carers have their needs formally assessed, so it is important to recognise the likelihood of extensive unmet need among carers. Detailed evidence about the situation of carers of working age, based on research in 2006-7, was presented in the CES Report Series (Yeandle et al, 2007).

¹⁹ In 2006/07, the *Commission for Social Care Inspection* (CSCI) introduced changes in the performance assessment process for English local authorities, replacing Delivery and Improvement Statements (DIS) with a Self-Assessment Survey (SAS - document no. 038/07, published Feb. 2007) in order to work 'towards a set of indicators that reflects outcomes for service user/carers' CSCI *Social Carer Performance 2004/05*.

²⁰ Carers' Grant does not represent all spending on services which support carers. Services to users, funded out of local authorities' Adults' Services and Children's Services core budgets, are also important in supporting carers.

Table 2: Carers' Assessments and Services: England		
1st April 2007-31st March 2008		
		<i>Figures rounded to nearest thousand</i>
Total number of carers recorded in 2001 Census of Population		4,855,000
Total number of carers assessed and reviewed		414,000
Carers assessed or reviewed separately		121,000
Carers assessed or reviewed jointly with client		256,000
Carers who declined assessment		36,000
Number of carers' assessments and reviews undertaken	ALL	378,000
<i>(by age of carer)</i>		
	<18	4,000
	18-64	194,000
	65-74	69,000
	75+	109,000
	Age unknown	2
Number of carers receiving services		337,000
	Receiving 'carer specific' services	209,000
	Receiving information only	128,000
Number of carers receiving services by age		
	All ages - 'carer specific' services	209,000
	All ages - information only	128,000
	'carer specific' services <18	2,000
	information only <18	1,000
	'carer specific' services 18-64	107,000
	information only 18-64	65,000
	'carer specific' services 65-74	38,000
	information only 65-74	24,000
	'carer specific' services 75+	60,000
	information only 75+	37,000
	Age unknown	3,000

Source: Community Care Statistics 2005-06: Referrals, assessments and packages of care for adults, England, HSCIC 2009a.

In England about two-thirds of assessments were of carers supporting people with a physical disability, frailty or sensory impairment, 38% of whom received a service. About half of the 48,000 carers assessed who supported someone with mental health needs - and a similar proportion of the 31,000 carers assessed who supported someone with a learning disability - received a specific break or service following their assessment (Table 3).

Table 3: Carers Assessments and Services by client group, England	
1 st April 2007-31 st March 2008 – <i>estimates based on local authority returns</i>	
Client group of cared for person	No. of carers
Physical disability, frailty and sensory impairment – Carers assessed	337,000
<i>Receiving breaks or carers specific services</i>	209,000
<i>Receiving advice and information only</i>	128,000
Mental Health – Carers assessed	46,000
<i>Receiving breaks or carers specific services</i>	31,000
<i>Receiving advice and information only</i>	15,000
Learning Disability – Carers assessed	35,000
<i>Receiving breaks or carers specific services</i>	24,000
<i>Receiving advice and information only</i>	8,300
Substance Misuse – Carers assessed	2,100
<i>Receiving breaks or carers specific services</i>	1,800
<i>Receiving advice and information only</i>	300
Vulnerable People – Carers assessed	8,500
<i>Receiving breaks or carers specific services</i>	5,800
<i>Receiving advice and information only</i>	2,800
% carers receiving services (not including advice and information only) following assessment or review	62%

Source: Community Care Statistics 2007-08: Referrals, assessments and packages of care for adults, England, HSCIC, 2009a.

Summary data on domiciliary and community services

Details of domiciliary care, community-based services and direct payments arranged through local authorities in England, indicating the volume of home services, the number of clients being supported in different ways, and recent, short-term, trends are shown in Table 4 (but do not include services provided to children).

Table 4 indicates that only about 25% of contact hours were supplied directly by CSSRs, and that only about 30% of households receiving home services got them directly from their local authority. This reflects trends towards outsourcing of services to independent providers (Yeandle et al 2006). The picture nevertheless varies greatly between CSSRs – some no longer providing any such services themselves. As noted earlier, the general trend over the past decade, in most English CSSRs, has been towards providing more intensive services, in a smaller number of households. There is widespread recognition, and considerable concern, about the amount of unmet need implied by this development, given other data on demographic and health trends.

Table 4: Domiciliary Care, Community-Based services and Direct Payments, England	
<i>Estimates for 2007-2008</i>	
Home services for adults*	
Contact Hours	
<i>All</i>	4,082,870
<i>Local Authority</i>	764,115
<i>Independent</i>	3,318,755
Households provided with services	
<i>All</i>	328,615
<i>Local Authority</i>	76,050
<i>Independent</i>	262,460
Number of clients	340,620
Households receiving intensive service¹	104,995
Contact hours of home help and home care per 10,000 households (% change 2007-2008)	
<i>All</i>	1,995
	(+5)
<i>Local Authority~</i>	375
	(-13)
<i>Independent</i>	1,370
	(+9)
Households receiving home help and home care per 10,000 households (% change 2007-2008)	
<i>All</i>	160
	(-2)
<i>Local Authority~</i>	35
	(-14)
<i>Independent</i>	130
	(+2)
Community-based services /direct payments**	
No. of clients receiving community based services	510,000
No. of clients from ethnic minority groups receiving community based services	52,000
No. of clients receiving Direct Payments	67,000
	(+38%)

Source: HSCIC, 2009a. ~ These figures may contain anomalies as the figure for home care delivered by the local authority includes services delivered to residents of supported housing, e.g. where a resident with a learning disability has their own tenancy. ¹ Defined as the number of households receiving more than 10 contact hours and 6 or more visits during the week.

1.3 Carers - the provision of unpaid care and support by family, friends and neighbours²¹

Carers in England have (as already noted) acquired a range of rights and entitlements and are offered a variety of support services. At local level, they may be able to access: respite or sitting services; advice and guidance; support in sustaining or entering education, training or work; a local 'carers' centre' or carers' information service; or supportive services targeted at carers in specific situations (such as carers of disabled children; young carers; carers of people with certain kinds of illness, disability or condition). However local services remain variable, patchy and insecure. Carers Grant has made a significant difference to some carers in many parts of the country, as we have seen, and has led to innovations, service enhancements and increased responsiveness to and engagement with carers and their locally expressed needs, but

²¹ The data here relate to unpaid carers – people who provide regular help to someone who need support because of illness, disability or frailty associated with old age.

local support still touches only a small minority of carers, many of whom remain isolated, unaware of their rights and entitlements, and cut off from the services and support to which they are entitled.

At national level, carers can (if they can establish eligibility), claim Carers Allowance (currently a very modest weekly sum, which the government has promised to review), and some other carers' benefits available through the national social security system. We have noted above that they also have certain legally protected rights: at work (to request flexible working); within the social care system (via assessments); and to equal opportunities.

However studies have repeatedly underscored carers' need for better information and services, and their difficulty in finding out about the support available. The government's 'New Deal for Carers' has produced a new (free) national telephone helpline for carers ('Carers Direct' went live on 1st April 2009, 7 days a week - however it is far too early to assess its impact or usefulness for carers), and some on-line services are also becoming available through the *Caring with Confidence* programme, which is seeking to support around 10,000 carers (over 3 years) via its on-line option. It seems reasonable to assume that ICT developments offer a way of improving carers' access to support, and we explore examples of this, in some parts of the country and in some national schemes, later in the report.

In Box 6 we outline some key characteristics of the carer population.²² The most reliable and recent data available about carers in England is derived from the 2001 Census of Population, which (for the first time) asked all residents to answer a question about their (regular) provision of unpaid care. This question, which is due to be repeated in the 2011 Census of Population, and will then provide important trend data about unpaid carers, has for the first time enabled researchers to investigate the circumstances of carers by key variables (sex, ethnicity, household composition and employment status, for example) at levels of detailed geography.²³ Carers' distribution by age and sex is shown in Figure 1. More detailed evidence, derived from the Census, is presented in a set of tables and figures included in the Appendix to this report.

²² This picture is derived from the 'snapshot' of carers taken in April 2001 when the last Census of Population was conducted. Carers are, however, a dynamic and (most experts believe) growing group, comprising large numbers of women and men, across a wide age range.

²³ CIRCLE has carried out comprehensive analysis of this data, investigating the distribution of caring responsibilities by ethnicity and many other variables. This analysis, presented in a wide range of previous publications, will remain the latest available data on this topic until the 2011 Census data becomes available in approximately 2013, see <http://www.sociology.leeds.ac.uk/research/care-employment/care-labour-equalities/>.

Box 6: Key facts about carers in the UK

- 11% of the population (almost 6 million people in the UK) provide unpaid care.
- Of these, almost 4.4 million are men and women of working age.
- 116,000 are children aged 5-15 years.
- 1.3 million are over state pension age.

The incidence of caring rises with age until men and women reach their 50s, remaining a common experience until well after state pension age.

- Women are more likely than men to be carers in all age groups under 75 years.
- A quarter of all women aged 50-59, and about 1 in 6 men, provide unpaid care.
- Men are more likely than women to be carers only when they are over age 75.

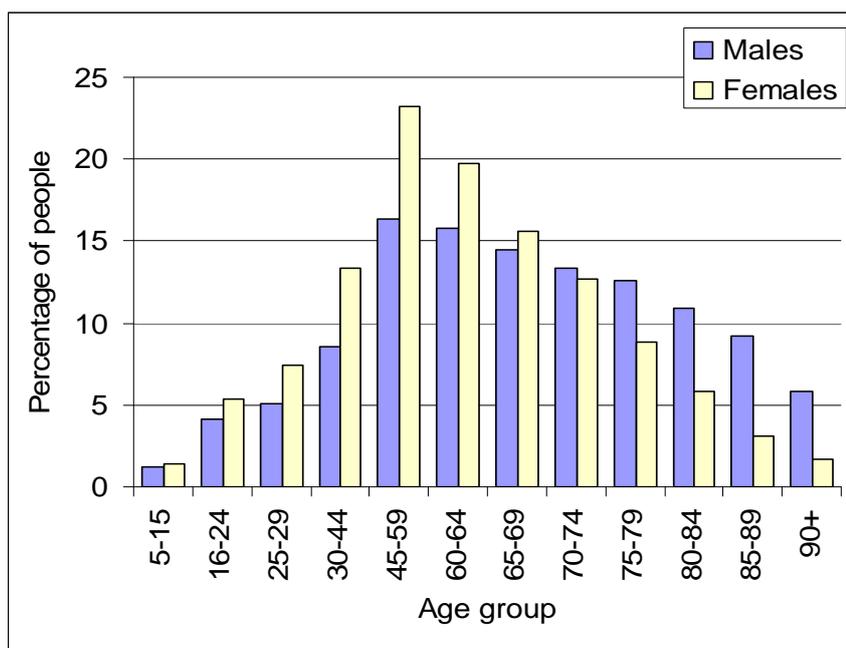
Weekly hours of care vary with age. Most carers provide their unpaid support for between 1 and 19 hours each week. However:

- One in twenty women aged 60-64, and
- Almost one in thirty men aged 60-64 provide more than 50 hours of care per week.
- Nearly one in twelve men aged 25-44, and
- Almost one in eight women in this age group has some unpaid caring responsibilities.

Source: *We Care, Do You?* Buckner, L and Yeandle, S (2005) – data sourced from 2001 Census, Standard and Commissioned Tables, Crown Copyright.

The 2001 Census also revealed notable variations in patterns of unpaid caring responsibility by ethnicity (see Appendix, Figures 2-5.) In some age groups more than 1 in 4 people provides regular care to an older, sick or disabled person, and the average for people of working age is much higher for people in some ethnic groups.

Figure 1: Provision of unpaid care at different ages, by sex



Source: 2001 Census Standard Tables, Crown Copyright 2003

Table 5: Key data about carers of working age	ENGLAND	WALES	SCOTLAND
Number of carers- ALL with caring roles	3,637,856	253,070	374,783
Carers who provide 20+ hours of care per week	1,012,721	88,510	124,681
Carers who provide 50+ hours of care per week	614,948	56,008	76,539
Carers in the population of working age, as % of all people of working age			
<i>All</i>	12	15	12
<i>Men</i>	10	13	10
<i>Women</i>	14	17	15
% of all carers who provide 20+ hours of care			
<i>All</i>	28	35	33
<i>Men</i>	25	33	32
<i>Women</i>	30	37	34
% of those caring 20+ hrs pw who are in poor health			
<i>All</i>	15	18	17
<i>Men</i>	18	21	18
<i>Women</i>	14	16	15
% of all carers who provide 50+ hours of care			
<i>All</i>	17	22	20
<i>Men</i>	15	21	20
<i>Women</i>	18	23	21
% of those caring 50+ hrs pw who are in poor health			
<i>All</i>	17	21	19
<i>Men</i>	20	24	25
<i>Women</i>	15	18	18

Source: 2001 Census Standard Tables, Crown Copyright 2003.

Table 6: Carers of working age by economic activity	ENGLAND	WALES	SCOTLAND
All people in full-time employment	55	50	54
<i>% of all men working FT</i>	70	64	67
<i>% of all women working FT</i>	39	35	40
All people in part-time employment	15	14	16
<i>% of all men working PT</i>	5	5	6
<i>% of all women working PT</i>	26	25	27
Carers in full-time employment	47	44	47
<i>% of all male carers working FT</i>	65	60	63
<i>% of all female carers working FT</i>	32	32	36
Carers in part-time employment	20	18	19
<i>% of all male carers working PT</i>	7	6	6
<i>% of all female carers working PT</i>	30	27	28
Carers caring for 20+ hrs pw in full-time employment	30	29	31
<i>% of all male carers caring 20+ hours pw working FT</i>	47	43	45
<i>% of all female carers caring 20+ hours pw working FT</i>	19	19	22
Carers caring for 20+ hrs pw in part-time employment	16	14	14
<i>% of all male carers caring 20+ hours pw working PT</i>	6	5	4
<i>% of all female carers caring 20+ hours pw working PT</i>	22	21	21
Carers caring for 50+ hrs pw in full-time employment	25	24	25
<i>% of all male carers caring 50+ hours pw working FT</i>	41	37	38
<i>% of all female carers caring 50+ hrs pw working FT</i>	14	15	16
Carers caring for 50+ hrs pw in part-time employment	14	12	12
<i>% of all male carers caring 50+ hours pw working PT</i>	5	4	4
<i>% of all female carers caring 50+ hours pw working PT</i>	20	18	18

Source: 2001 Census Commissioned Tables, Crown Copyright 2003.

1.4 Care workers²⁴

In England, the 2001 Census recorded almost 445,000 people of working age who were in employment²⁵ as care assistants and home carers.²⁶ Table 7 shows that this included about 209,000 people working in full-time jobs and about 227,000 in part-time employment. There were also about 9,000 self-employed people in England working in this occupational category. The average number of care workers stood at 9.1 per 1,000 total population in England, however this varied quite markedly between localities. Detailed data showing evidence of local variation (prepared in a separate study in 2006) are presented in the Appendix to this report.

Characteristics of care workers

The workforce in social care was highly feminised, with approximately 90% of all positions as care assistants and home carers in England held by women, the precise percentage varying between different localities. Fifty-four per cent of all care worker jobs were held by women aged 25-49 and 22% of care worker jobs were held by women aged 50-59. However this also varied considerably between one locality and another.

Table 7: Care workers and care assistants, by form of employment and sex: England	
Women	
Part-time employees	215,383
Full-time employees	170,613
Self-employed	7,354
Total women	393,350
Men	
Part-time employees	11,636
Full-time employees	38,153
Self-employed	1,797
Total men	51,586
ALL	444,936
Number per 1,000 people	9.1

Source: Yeandle et al 2006, 'Local Challenges in Meeting Demand for Domiciliary Care: Synthesis Report' – data derived from 2001 Census Commissioned Tables, Crown Copyright 2003.

Older women workers were disproportionately concentrated in care work. In England as a whole, women aged 50-59 held only about 9% of all jobs in the economy, but occupied 22% of all care worker jobs; again there was considerable variation from this figure in some localities.

There was a very uneven representation of ethnic groups in the care work sector, mirroring divisions by ethnicity seen in other parts of the economy. In care work there were also some very interesting gender divisions. Among women, just over 10% of all care worker positions were held by women from ethnic minority groups. This figure rose to over 30% in some areas and was highly variable between different localities, in part reflecting the size of the ethnic minority population in each area. In some localities, women from ethnic minority groups (considered together) were more concentrated in care work than in all jobs, but this was not true everywhere and depended upon the precise composition of the ethnic minority population

²⁴ This section of the report draws heavily on Yeandle, S. et al (2006).

²⁵ This includes those who are self-employed.

²⁶ Note that in these data, it is not possible, for technical reasons, to distinguish between those providing care in residential and domiciliary environments.

in each locality. Black African and Black Caribbean women were disproportionately concentrated in care work almost everywhere, and in some places the 'White Other' group (which includes people from other European countries, as well as a number of other categories) was also highly concentrated in this occupation. By contrast the Indian, Pakistani and Bangladeshi population groups of women tended to be under-represented in care work, irrespective of the locality in which they lived.

Examination of men and ethnicity in relation to care work reveals that ethnic minority men were disproportionately concentrated in care work in most localities (see Appendix). Detailed analysis reveals that men from the Black and Black British groups were quite strongly concentrated in care work, whereas men of Asian origin were rather less likely than other groups to take up employment in this sector.

Among both men and women care workers, there was a comparatively high level of part-time employment. This characteristic of care work was at least as strong a feature of the sector among male workers as for female workers. The variations between different localities reveal some interesting gender differences.

In 2001, 20% of all male care workers, and just under 30% of all female care workers, were unqualified. As already indicated, there has been a strong policy steer at national level in the past decade to create a more demonstrably skilled workforce in social care, with national targets set.

Having outlined the main characteristics of both the carer and domiciliary care worker populations, and the broad social policy context framing their experiences, we turn now to a more detailed focus on the policy environment for domiciliary care. It should be borne in mind that many domiciliary care workers provide support for a service user who also has an unpaid carer providing additional (and often most of their) support.

1.5 The policy environment for domiciliary care in England²⁷

As indicated in the opening section of this report, the social care system in England has undergone significant changes in the past two decades, including changes in local authorities' responsibilities as service providers and as employers. Local authorities' primary role in this field is now to commission and purchase social care services, and to contract with independent service providers.

The total number of hours of domiciliary care provided in England doubled between 1993 and 2005, reflecting government policies promoting independent living and care at home, as well as substantial growth in the number of older people living in single person households. A clear trend towards delivery of more intensive packages of care, with far fewer households receiving only a single visit or less than two hours of care each week could be observed (NHS 2006).

These developments were initially set in train in *'Caring for People: community care in the Next Decade and Beyond'* (a 1989 government White Paper), which outlined radically different funding arrangements for social care, and emphasised that care should be tailored to individuals' needs. As mentioned in Part 1, the 1990 *NHS and Community Care Act* which took this policy forward, required English local authorities to make use of private and voluntary sector provision, bringing into being a 'mixed economy' of care. In addition to the key features already outlined, subsequent developments affecting care in home settings have included:

²⁷ Some of the material in this section is reproduced from Yeandle, Shipton. and Buckner (2006).

- A *Royal Commission on Long-Term Care for the Elderly* set up in 1997 to examine the funding of long-term care in the context of population ageing, taking a wide range of evidence and making recommendations in 2000. In England, the government rejected the Commission's recommendation that (in addition to providing 'nursing care' free of charge) 'personal care' should be free in response to assessed need. It was argued that 'free personal care' would be excessively costly for the public purse and unsustainable.
- The White Paper *Modernising Social Services* (Department of Health, 1998) which called for more co-operation between health and social care agencies, highlighting the need to reduce geographical variations in performance/quality of care. Greater promotion of independence was advocated, to be achieved in part by the extension of Direct Payments²⁸ to people over 65. National objectives, standards and targets for quality and efficiency were set for Social Services Departments.
- The *Care Standards Act 2000*, which established a *National Care Standards Commission* (April 2002, later incorporated into the Commission for Social Care Inspection). This had responsibility for setting, regulating and inspecting all regulated care services, including domiciliary care.
- The *General Social Care Council (2001)* became the workforce regulator for social care in England. It was established as the independent regulatory body responsible for overseeing social care training, and is tasked with raising standards of conduct and practice by setting requirements for training, qualifications and professional development as well as by registering domiciliary care staff (in a phased development which began in 2005).
- The *Social Care Institute of Excellence* was launched in October 2001. An independent registered charity, its role is 'to develop and promote knowledge about good practice in social care'. The SCIE runs a free on-line resource, *Social Care Online*, targeted at practitioners, researchers, service users and policy makers and aims to highlight good practice and identify information about the sector.
- *The National Service Framework for Older People (2001)* was established to improve the quality of care services by exploring the problems older people encounter in accessing and receiving care. The Framework included plans to eliminate age discrimination and to support person-centred care with newly integrated services.
- *Better Government for Older People (2004)* was established as a networking partnership in which older people are the key partners. Part of the wider *Modernising Government agenda*, this partnership aims to ensure older people are engaged in the development of strategies and services supporting an ageing population.
- In line with the *Health and Social Care (Community Health and Standards) Act 2003*, a *Commission for Social Care Inspection* was launched in April 2004 as the 'single, independent inspectorate for all social care services in England'. The CSCI drew together 'the inspection, regulation and review of all social care services' and published an annual *State of Social Care* report (2005 – 2009). The CSCI merged with the Healthcare Commission to form a new *Care Quality Commission* on April 1st 2009.
- The *Fair Access to Care Services (FACS)* initiative (introduced following a consultation in 2001 with implementation required by April 2003) addressed inequalities in how eligibility criteria are defined and applied for adult social care services. Its framework is based on individual needs and associated risks to independence. It aims to achieve fairer and more consistent eligibility decisions across the country. In 2008 the government asked

²⁸ For a detailed discussion of the Direct Payments (cash for care) scheme in England, see Yeandle and Stiell (2007).

CSCI to review the implementation of FACS and a report on its findings: *'Cutting the Cake Fairly?'* was published in October 2008.²⁹

- *Skills for Care* was established in April 2005, and is led by employer networks and other care interests. Part of the *Sector Skills Council for Care and Development*, and now regulated by the *UK Commission for Employment and Skills* (UKCES), it replaced the *Training Organisation for Personal Social Services* (TOPSS). Concerned specifically with adult social care, Skills for Care aims to support employers by improving the quality of care provision through training and development, workforce planning and workforce intelligence. It has responsibility for the NMDS-SC (the National Minimum Dataset for Social Care³⁰).
- In 2006, the White Paper *Our health, our care, our say: a new direction for community services* (Department of Health, 2006) set out plans for a 'radical shift in the way services are delivered', establishing a new direction for the health and social care system, featuring more personalised services, with the client the main major driver of service improvement. This followed the Green Paper *Well-being and Choice - our vision for the future of social care for adults in England* (Department of Health, 2005b), which called for the introduction of 'individual care budgets' and new brokerage arrangements to support care users.

Subsequent developments relating specifically to ICT and telecare are outlined in Part 3 of this report.

Delivering domiciliary care

The delivery of domiciliary care has been identified as a key issue in contemporary public policy in recent years (Robinson and Banks, 2005) which affects the well-being of millions of older and disabled people and their (unpaid) carers and involves large numbers of paid domiciliary care workers (McClimont and Grove, 2004). Organisations involved in the provision of domiciliary care in England include companies, local authorities and charities. There were 4,897 domiciliary care agencies registered with CSCI in 2008 (CSCI, 2009), a notable increase from the 3,684 agencies registered in 2004 (Eborall, 2005). Other key agencies include the 150 CSSRs discussed in Part 1 (which purchase a large volume of services from these providers, some of them also continuing to employ some domiciliary care workers themselves); and a wide range of sector/professional bodies, trade unions, regulatory and/or advisory agencies and training providers in this field. The quality, adequacy and reliability of domiciliary care is of critical importance for the welfare of many vulnerable

²⁹ CSCI notes on its official website: "Our findings demonstrate that the current system of determining eligibility is both heavily criticised and not aligned with present policy. The number of people seeking care and support has been rising and will continue to do so. Whilst most people accept that not everything can be provided by the State, they want a fairer and clearer system and one which both promotes their well-being and, if they need care and support, enables them to make informed decisions about the options available. Our review indicates there is some way to go before everyone can benefit from that approach." The review found that some people are benefiting from council-funded schemes aimed at those falling below local eligibility criteria. However, the overall picture confirms that people looking for support frequently fail to have an opportunity to have their needs properly taken into account and advice about the choices open to them. People who do not meet the eligibility criteria manage as best they can but often at great cost in financial, emotional, personal and physical terms, both to them and their family carers (22 October 2008).

³⁰ The NMDS-SC statistics are produced to meet the needs of employers and social care organisations and to assist in the development and workforce planning of the social care sector. The statistics are presented as pdf files in three volumes and can be accessed from <http://www.nmds-sc-online.org.uk/news/View.aspx?87>. Using the sets of standard cross-tabulations, users can look at the sector as a whole, or look at particular care-settings in detail, for example care-only homes, care homes with nursing or domiciliary care.

older and disabled people, relies heavily on the organisational standards and effectiveness of providers, and impacts on a wide range of other social and economic issues.

Based on studies completed in 2002 and 2004 by the *UK Home Care Association (UKHCA)* (McClimont and Grove, 2004), which surveyed some 4,500 providers,³¹ the UKHCA found an increase in the proportion of providers reliant on local authorities for their business, with many small providers entirely dependent on this source. It reported 65% of the home care workforce was employed in the independent sector, noting:

Only 6% worked for more than one home care organisation, down from 14% in 2000, and only 11% had other types of paid work, down from 22%. A reduction in the prevalence of casual workers and those holding multiple jobs may be viewed as very positive, offering greater continuity and making investments in training and development more economic. However, the higher utilisation rate of worker time and the disappearance of the 'reserve' of casual workers could indicate loss of ability in the sector to absorb future increases in demand. (2004: x)

The UKHCA study also found a reduction in the number of new recruits entering the sector (14% compared with 22% in 2000), and that:

Three-quarters of providers... reported difficulty in recruiting home care workers or with retention. The most commonly cited problem was the general shortage of labour in the market. (2005: xi)

Box 7: Home care and carers

- In 2006-07, £2.36 billion (net) was spent on homecare and accounted for 46% of all community services expenditure. This is a 2% increase in expenditure in real terms from 2005-06, but represents a significant fall from an annual year-on-year increase of nearly 10% in the years from 2002-03.
- 198,000 carers aged 18-64 and 189,000 aged 65 and over were offered an assessment or review in 2006-07; 7,000 (2%) more, in total, than the year before. About 1 adult in 4 who received a community service in the year had a carer who was offered an assessment or review. 178,000 carers received a service following their assessment or review. Some 7,700 carers used a Direct Payment as at March 2007. Breaks for carers, reported by councils, increased by 15% from 2004-05 to an average of 20,520 per council in 2006-07.
- The number of registered home care agencies has risen each year since 2004 reflecting the trend towards providing care to people in their own homes. There were 4,897 registered home care agencies at the end of March 2008.
- The home care sector continues to be made up of many small home care providers with most having fewer than 100 people using their service. The prevalence of small agencies makes this sector particularly vulnerable at the present time. The private sector dominates the home care market with over three quarters of home care agencies in private ownership.

Between April to September 2007, was rated as 'adequate'; 88% received services from a home care agency rated as 'good' or 'excellent'. In all, 3,700 people were receiving home care from services rated as 'poor', and a further 24,000 receiving their care from services rated as 'adequate'. One person in seven received a home care service from an independent sector provider with a published rating of 'poor' or 'adequate', as compared with almost one in 20 with a service from a voluntary organisation.

Extracts from the 'State of Social Care' Report (2008)

³¹ The UKHCA survey had a 20% response rate among organisations (producing data from 727); a 9% response rate among care workers (with nearly 3,000 care workers questionnaires returned); and a 16% response rate from Registered Managers (561 returned).

Since 2005, the CSCI's annual publications entitled *The State of the Social Care* have become an important source for information on the social care workforce and conditions in the sector. In 2005, CSCI estimated that the independent sector domiciliary care workforce at 106,500 people of whom 97,500 were care workers, noting that vacancy rates in social care were about twice as high as for private/public sector business activity generally, that rates of pay were low although care workers in the public sector earned on average 22% more than those in the independent sector, and that knowledge of the independent sector workforce, and about levels of qualification and training in the workforce remained inadequate.

By 2008, in its final *State of Social Care* report, CSCI recorded a total of 290,625 care workers in England. Key statements from this report are included in Boxes 7 and 8. As indicated, while most users of home care services indicate that they are satisfied with the standard of service they receive, a small minority of provision was, when last monitored, considered to be 'poor'.

In Box 8, which reports an increase in Personal Assistants, we see the emerging impact of the extension of the Direct Payments Scheme to a larger number of older and disabled people, and of the introduction of Individual Budgets (through a series of pilot projects), which in some cases involve the use of PAs.

Box 8: The adult social care workforce

- The adult social care workforce in England is estimated at 1.5 million workers, an overall increase of 8% since 2006-07. Numbers employed in adult social care by councils fell from an estimated 228,000 in 2006-07 to 221,000 in 2007-08. Numbers working in the independent sector increased from an estimated 988,000 to 1,070,000, and in personal assistant roles from 113,000 to 152,000.
- The number of vacancies notified to Job Centres for care workers, social workers, occupational therapists and other care and support-related occupations exceeded 100,000 in the second half of 2007 and has remained at these high levels during the first half of 2008.
- Over 80% of vacancies are for care workers. Council workforce vacancy and turnover rates were 8.6% and 10.0% respectively in 2007-08, little changed from 2006-07 when the corresponding rates were 8.4% and 10.3%.
- The independent sector has a turnover rate of 17.9% for all staff and a vacancy rate of 3.8%. These rates are higher in home care settings, with turnover rates of 20.7% for all staff and vacancy rates of 5.2%.
- In 2007 just over 66% of care workers had obtained the equivalent of an NVQ level 2 or higher, while around one third had not obtained a level 2 qualification. This is an improvement on 2006 levels when fewer than 60% had an NVQ2 or equivalent.

Extracts from the 'State of Social Care' Report (2008)

Difficulty in recruiting home care workers has been widely reported by local authorities (Yeandle et al 2006); as indicated in Box 8, both turnover rates and vacancy rates for home care workers remain high; qualification levels continue to fall short of national targets for minimum standards, but continue to improve.

Our expert interviews and review of documentary sources confirmed that key agencies continue to express concerns about the ability of the home care sector to meet need. The President of the UK Homecare Association noted the 'tremendous importance' of telecare as one of the developments affecting service delivery and the quality of outcomes for users and carers. Highlighting some ambivalence among providers and home care workers about its role

(some fearing it might ‘replace a caring relationship with technology’), her overall assessment, based on wide experience in the sector, as a carer, and as a member of the Telecare Network, was that telecare ‘has an important role’. However in mid-2009 ‘the infrastructure needed to support effective use of telecare by home care agencies ‘was not yet in place’.

In Part 2 of this report, we look more closely at the way ICT and telecare developments have developed in England and across the UK.

2. ICT developments designed to support care and carers

In Part 2, drawing on our expert interviews and other contacts with relevant agencies, and on our review of policy documentation, we outline a range of ICT and other related developments which have been put in place in England to support carers, those they care for, care workers and other social care professionals, often with a view to introducing efficiencies and quality improvements into the English system of social care. We also briefly outline several specific policy developments in England which have the potential to provide support for carers and care workers in domiciliary settings: the English *Preventative Technology Grant*; the new *Caring with Confidence* programme, which has on-line and self-study versions for carers; the emergence of online forums and help-lines offering support to carers; and the *Whole Systems Demonstrator* projects which have been developed in some parts of England.

Before turning to this material, however, we first summarise some of the findings highlighted in our review of recent English language academic journal articles, which offer a critical commentary about both the potential and the limitations of ICT-based initiatives within the social care system (for details of the methodology see appendix 4).

2.1 Telecare and telehealth development: evidence from a literature review

Our review confirms that ICT is now widely viewed as having a major role to play in the future of social care, with implications for carers and care workers as well as for service users. Many studies have already been undertaken, with a growing number of academic papers published, and although these often present evidence from pilot projects, where findings are necessarily tentative or inconclusive, some clear messages are also beginning to emerge. It should be noted that it has not been possible in this report to comprehensively review all relevant literature; what follows simply indicates some features of particular relevance to the present investigation.

Early findings from studies and projects relating to ICT in social care reveal a number of potentially important issues for the development of these technologies. For example, one study reviewed a number of ‘trigger factors’ traditionally associated with older people (falls, failure to take medication, etc.) and asked an expert panel to rank these in terms of how telecare services might help (Brownsell et al, 2007). These experts judged that telecare equipment could assist, prevent or minimise 66% of the ‘top 36’ triggers, and 75% of the ‘top 12’ triggers. This study thus strongly suggested that telecare has a potentially valuable role to play as a component of future care packages in the case of older people.

Another study (Levy et al, 2003) noted that older people under the age of 80 years old tended to be most receptive to the use of telecare equipment, suggesting that this was related to both their willingness to engage with new technology and their desire to remain in their own homes. Mihailidis et al (2008) also found that the desire to remain in their own homes was the critical factor for older people in relation to using telecare equipment. Onor et al (2008) compared older people’s experience of, and satisfaction with, three types of care: a day care centre, a nursing home, and a telecare service. Their questionnaire data showed 98.5% of older people taking part were satisfied with the telecare service, compared with 75.3% of those residing in a nursing home and 76.5% of those attending the day care centre.

Other studies have highlighted variations in the extent to which older people feel comfortable using telecare equipment. Bertera et al (2007) issued 85 older people with a self-administered questionnaire and found that while they were willing to engage with technology which put

them more easily in touch with a doctor or a nurse, they were less willing to use equipment perceived to be invasive in their homes (e.g. use of cameras for monitoring, etc).

A study published by Kent County Council (2006) also revealed that some users of telecare equipment and their carers were concerned about the ‘big brother’ element involved in equipment designed to monitor patients, although telecare equipment was regarded as valuable in certain conditions. This finding was corroborated by Mair et al (2006) whose study showed that while patients preferred ‘face to face’ medical attention in the case of acute illnesses, telecare services were considered more acceptable by people suffering from chronic conditions. Telehealth trials have also shown that an experimental group of clients with heart disease was more likely to follow a strict diet than those not using telecare equipment (Lindsay et al, 2008).

Many studies have concluded that most patients prefer a combination of both traditional ‘face to face’ services and suitable, non-intrusive telecare equipment (Botsis and Hartvigsen, 2008). Kent County Council’s research showed user perception of telecare to be very positive: older people felt telecare gave them a sense of security, offered them independence and worked well in emergencies. They did not find the equipment stigmatising, although the study found few wore equipment such as emergency-button pendants all the time. Some were put off by the design of the technology available: for example, some users in this study regarded the fall detectors as ‘bulky’. It is also worth noting that in this study, few users felt they had been involved in decisions about the installation of telecare equipment in their homes.

Research on carers’, rather than service users’, reactions to the introduction of telecare equipment has also found mixed responses. Rahimpour et al (2008) found that while many carers reported that appropriate telecare equipment reduced their anxiety and gave them more recreational and occupational freedom in their everyday lives, some expressed concerns about the potentially ‘de-humanising’ aspect of these services, and noted concerns about the cost and ease of use of the equipment installed, as well as about the level of clinical support available. Some carers of older people with dementia who were being supported with telecare noted concerns that the equipment could exacerbate their difficulties in providing care, if it generated repeated call-outs from the service user (who, in the same circumstances, would previously have been unable to indicate that assistance was required). They felt this could result in attending the person they cared for more regularly (Kent County Council, 2006).

In a trial telecare project supporting patients with chronic obstructive pulmonary disease (COPD), Mair et al (2005) found that the nurses involved were less positive about telecare than their patients. However other healthcare professionals have found telecare services liberating in their working life. One study on telemonitoring (Terschuren et al, 2007) showed that GPs who had formerly needed to visit older patients to conduct monitoring procedures could delegate these responsibilities to nurses by a system of service user reports conducted by telephone. This resulted in time saved, mainly through reducing the travel involved. Nesbitt et al (2006) studied telecare services used in four rural areas and also revealed that nurses’ travelling time could be significantly reduced by the implementation of home-monitoring equipment. In this study, the condition of the service user also improved, a change thought by the nurses involved to be due to the use of telecare equipment.

Several studies of the role of ICT in facilitating communication and training in social care are also reported in the literature. In their review of articles on ICT, Garcia-Lizana and Sarria-Santamera (2007) showed that while ICT applications did not improve (or adversely affect) clinical outcomes for sufferers of asthma, hypertension, diabetes, heart disease and heart failure, there was nonetheless a positive impact on education and social support for users of ICT-based equipment. Brownsell et al (2008) also found that while an intervention aimed at older people using telecare sensors and an Internet Café did not reduce the fear of falling and

other anxieties, it did result in better social functioning. Service users spent more time away from home, and 25% used the Internet Café for at least 20 minutes per week.

In another study, of carers living with an older person with a chronic condition, the ICT equipment in place did not directly reduce carer stress and mental health problems, but did lead to carers reporting more social contacts, increased support and less need for information about chronic illness (Torp et al, 2008). The additional contact with other carers and family, facilitated by the ICT equipment, was also regarded as valuable by the carers in this study. Akeson et al (2007) also found that ICT-based initiatives led to consumers feeling better informed and more 'empowered' by the improved access to information made possible by these schemes, and that the carers involved did not fear telecare and ICT services would replace traditional 'face to face' service delivery. Other studies have found that ICT-based interventions can result in reduced carer stress and depression, although the effects reported varied for different groups of carers, by ethnicity, amount of formal support available, and baseline levels of 'burden' (Powell et al, 2008).

Similar findings emerge from studies assessing the impact of ICT initiatives on care workers. A review of ICT-based initiatives aimed at physicians (including postgraduate trainees) showed that the use of the Internet for audit and feedback, and email for patient-provider communication, had mixed effects (Gagnon et al, 2009). Four of the studies they reviewed demonstrated 'small to moderate' positive effects of ICT interventions, while four other studies showed no effect. Two further studies had 'mixed' effects. However it should be noted that none of the studies these authors reviewed considered the long-term effects or sustainability of the interventions. They concluded that, at present, there is little evidence available to support the development of ICT initiatives for social care professionals.

As indicated in this exploratory review, research on the use of ICT equipment is still at a relatively early and inconclusive stage of development. Koch (2006) argues that much work remains to be done to evaluate the impact of telecare and ICT interventions. Robust studies are still needed to explore impacts and benefits, examine the limitations of potential solutions and propose practical guides to implementation (including legal, ethical, organisational, clinical and technical components). Nevertheless it is evident that the available evidence base is expanding rapidly, indicating benefits of different kinds for different stakeholders. Percival and Hanson (2006) argue that, for telecare services to be properly developed to meet the needs of service users, carers and healthcare professionals, policymakers must consult all stakeholders, paying particular attention to individual choice, surveillance, risk-taking and quality of service. An example of the positive impact such consultation can have is demonstrated by Hibbert et al (2003), whose study showed how a telenursing service was improved and refined (particularly with regard to its 'user-friendliness'), using feedback from the nurses involved in implementing the system.

Finch et al (2005), who interviewed 38 key informants with an interest in telecare: policymakers, clinicians, technologists, health service managers, researchers and patient advocates, make a similar point. A major problem perceived by these authors was that priorities in this field are 'assumed' rather than based on empirical evidence derived from service users, carers and professionals. In a separate study, the same authors interviewed a similar group of informants, noting limited understanding among them of: how, in practice, service users relate to ICT; how they might be involved in decision-making; and how ICT might fragment care and medicine in unexpected ways (Finch et al 2008).

Basing their judgment on a pilot telecare scheme in the UK, Barlow et al (2003) suggested over five years ago that telecare services needed to be designed so that detailed evaluation of all their components was possible, with careful thought given to how an ICT-based service can be integrated with the existing care system. More recently, Broens et al (2007) have

argued that a ‘visionary approach’ is required from multiple stakeholders, proposing a ‘layered integration model’ in which individual components can change throughout the developmental life cycle of an ICT-based project. As we show below, government has taken note of this point, implementing several major initiatives designed to improve the quality of the available evidence base.

Yee et al (2008) argue that the current generation of service users, carers and professionals are eminently placed to make real progress with ICT-based initiatives in social care. They point out that socio-cultural change is required to guide the design and implementation of successful ICT solutions for a sustainable healthcare future. Nevertheless some other authors continue to issue a note of caution. Bayer et al (2007) claim it is important not to be over-optimistic with regard to the potential of ICT to overcome short-term problems, and that its benefits will take some time to be realised. Loader et al (2008) warn of possibly ‘expensive and ineffective outcomes’, if the paucity of clear evidence that ICT can deliver significant positive change to existing healthcare services is not addressed.

2.2 Policy initiatives

Although telecare initiatives and enhanced use of ICT in the social care system have existed in England for well over a decade, with a number of local pilots and projects put in place in the 1990s, and telecare mentioned in the first National Strategy for Carers (1999), in England the major official impetus to these developments has been developed only in the past 5 years. Government announced a new funding stream for local authorities *Preventative Technology Grant* in 2004, and following this, in July 2005, the Department of Health published ‘*Building Telecare in England*’, a major policy document which the Department introduced with the official statement:

Telecare offers the promise of enabling thousands of older people to live independently, in control and with dignity for longer. This document provides local authorities and their partners with guidance in developing telecare services for their communities. It sets out the purpose of the Preventative Technology Grant and sets out expectations for the use of the grant.

In this part of the report, we highlight some of the developments associated with this policy initiative, noting the role and activities of:

- the introduction of the *Preventative Technology Grant*;
- the *Care Services Improvement Partnership (CSIP)*;
- the creation of a *Telecare LIN (Learning and Improvement network)*;
- and the setting up of three *Whole Systems Demonstrator* projects.

Preventative Technology Grant

In 2004 the Government announced plans to invest £80 million (over two years, beginning in 2006), through a new *Preventative Technology Grant*. Through the grant the government expected local authorities in England to invest in telecare to help support people in their local communities, with a view to helping 160,000 older people in total nationwide. The grant was allocated to all English CSSRs, using the Spending Share for Older People Formula.³² £30 million was made available in 2006/7, and a further £50 million in 2007/8. The grant was intended to be used to ‘pump-prime’ telecare projects which would become ‘sustainable’ in the long-term. In implementing this initiative, local authorities were expected to work with

³² A formula used for the annual allocation of funds local authorities receive from government in relation to different user groups. A similar scheme was also introduced by the Scottish Government (and is briefly outlined, below).

their partners in housing, health, and in the voluntary and independent sectors as well as with service users and carers.³³

Preventative Technology Grant

Extract from *Building Telecare in England* (Department of Health, 2005a):

The grant is designed to help local authorities and their partners address the challenges of a changing and ageing society with increased expectations, such as the right to have choice about services, control over their delivery and the right to be able to live independently at home with dignity for life. By helping co-ordinate our approach, the grant seeks to create the best possible atmosphere for the new telecare industry to flourish.

Expected outcomes:

The grant should be used to increase the numbers of people who benefit from telecare, by at least 160,000 older people nationally. Its use will:

- *Reduce the need for residential/nursing care;*
- *Unlock resources and redirect them elsewhere in the system;*
- *Increase choice and independence for services users;*
- *Reduce the burden placed on carers and provide them with more personal freedom;*
- *Contribute to care and support for people with long term health conditions;*
- *Reduce acute hospital admissions;*
- *Reduce accidents and falls in the home;*
- *Support hospital discharge and intermediate care;*
- *Contribute to the development of a range of preventative services;*
- *Help those who wish to die at home to do so with dignity.*

Increased reassurance for service users and carers resulting from the use of telecare will release services from constraints created by risk-averse policies and practices. In doing so, this will enable them to become more responsive to the lifestyles of individuals.

Deployment of the grant is also expected to contribute to the wider health, housing and social care policy agenda, including delivering on National Service Frameworks (NSFs), the NHS system reform agenda and the new Vision for Adult Social Care.

In 2006 a National Framework Development was negotiated by the *NHS Purchasing and Supply Agency* (NHS PASA) to support the Department of Health's vision of building a strong telecare infrastructure.³⁴ NHS PASA launched a four year (2006-10) contract for telecare products and services, covering telecare equipment, installation, maintenance, monitoring and response services. Telecare equipment is provided to support an individual in their home and tailored to meet their needs. It covers a wide range of equipment/services, including: detectors; monitors; alarms; pendants; monitoring; call centres; and response services.

The agreement in place has been developed under the guidance of a wide variety of stakeholders throughout health, local authority and government organisations, with the aim of reflecting the needs of all users. It can be used by all government bodies involved in healthcare, as well as other organisations:

³³ There is growing evidence that this has begun to happen. For example, in the city of Leeds the telecare service established using the Preventative Technology Grant has since 2009 been funded from mainstream local authority budgets including *Supporting People* (source: key informant, communication June 2009)

³⁴ <http://www.pasa.nhs.uk/PASAWeb/Productsandservices/Telecare/NFA.htm>

- Local authorities and social care in England
- NHS trusts, strategic health authorities, collaborative procurement hubs, supply management confederations
- Housing organisations/associations
- Voluntary sector and/or charitable organisations
- community equipment services, independent sector providers (such as third party organisations/partners)
- non-departmental bodies charged with the delivery of health and social care/services.
- equivalent organisations in Scotland, Wales and Northern Ireland.

By negotiating a single contract on behalf of government bodies, NHS PASA has removed significant cost from the process both on behalf of users and suppliers. The intention is that users will benefit from:

- competitive pricing
- a ready-to-use agreement, with no need for separate tendering
- access to an electronic catalogue with supporting pictures / descriptions / prices
- choice of a wide range of suppliers, products and services.

Care Services Improvement Partnership

The *Care Services Improvement Partnership* (CSIP) was commissioned by the *Department of Health* and other agencies to help services implement national policies, including the 2005 White Paper '*Our health, our care, our say*', which outlined changes for health and social care services, calling for greater 'personalisation' and a better fit between health and social care services and people's everyday lives.

CSIP was created in April 2005 and ran for four years, ceasing to exist 'as a brand' on 31 March 2009 (when its main work moved to the Department of Health's 'Putting People First' team within the DH Care Networks directorate). It worked with health, local government, public, voluntary and private sectors to improve services and the health and wellbeing of children and families, adults and older people in England. The official statement of its objectives included its responsibility to support:

- the improvement of services to achieve better outcomes for people who use them and their families and carers
- people to live more independently by promoting more choice, control and equality
- system reform, the way in which health and social care fit together to achieve a more joined up experience for people.

CSIP as an entity ceased operations on 31 March 2009. However, its work will be carried forward through a range of programmes, including the *National Mental Health Development Unit*, *Care Networks*, the *DH Health and Social Care Change Agent Team*, and the *Long term conditions community*.

Telecare LIN

The Telecare LIN is England's national network supporting local service redesign through the application of telecare and telehealth to aid the delivery of housing, health, social care and support services for older and vulnerable people.

Information provided in an expert interview with this agency suggests that, from 2005 onwards, the *Building Telecare* agenda has given specific attention to the 'balance between

personal care and what telecare can do'. In England, most telecare services support users who have a care plan in place (which, as shown earlier in the report, in most CSSRs means someone whose needs have been assessed at 'substantial' or 'critical' level). These users tend to need personal care of the kind which has to be delivered by a person, *in situ* – and although it was always recognised that telecare might replace some kinds of support (e.g. some overnight stays by carers/care workers), for this type of user it is important to recognise that telecare support and directly delivered personal care are likely to continue to go 'hand-in-hand'.

While evidence reviewed via the Telecare LIN suggests that, in theory, domiciliary care workers could assist service users to access and use telehealth applications, there is currently no real evidence that this is yet taking place, partly because of 'structural barriers' which limit domiciliary care workers' role. In 2009, the number of telehealth installations in England remained quite small, at approximately 5,000 nationally, compared with the much larger number - some 1.5 million - telecare users.³⁵

Some small experiments have been set up with domiciliary care workers using phone call / webcam support to remind care users to take medication, attend appointments, etc., and some CSSRs now have arrangements in place to monitor low temperatures within the home and even to enable the *Metereological Office* to alert social care agencies when people with conditions such as COPD should not go outside because of weather conditions. Some agencies have also introduced a '*Just Checking*' system, in which sensors are installed around the home, and used in conjunction with a 24/7 web browser screen. Usually these are used to check use of kitchens and bathrooms.

Whole Systems Demonstrators

In May 2007, the government announcement that the counties of Kent and Cornwall and the London borough of Newham had been selected as the three *Whole System Demonstrator* projects. Designed as large-scale pilots testing new models of care, these projects were set up to enable government to 'confidently meet the challenges posed by an ageing population and the associated increase in prevalence of long term conditions'.

Since 2007, a *Department of Health* programme team has worked closely with each of these sites, their delivery partners, project management partners and its evaluation consortia to develop and implement the plans.

³⁵ This figure includes those supported by a community alarm, without additional telecare equipment.

The Whole Systems Demonstrators (WSD) Programme

Adapted from DH website

All three WSD sites are recruiting GP practices to take part in the WSD programme, through targeted information, practice visits and roadshows. Ultimately there will be over 7000 telecare and telehealth installations in individuals' homes, making the WSD programme the largest trial of telecare and telehealth in the UK to date. Each site will recruit over 1000 patients/users for telehealth and over 1,000 patients/users for telecare.

The official aim of the WSD Programme is to understand the true benefit of integrated health and social care supported by advanced assistive technology (telehealth and telecare), and a robust evaluation has been identified as the key to proving the business case for the investment needed.

The evaluation is being provided by a consortium of UK universities, using a methodology which has been designed to be extremely robust, featuring a Randomised Control Trial, and focusing on individuals with Chronic Pulmonary Disease (COPD), Heart Failure and Diabetes, and adults with social care or health and social care needs at risk of hospital admission. It will look at the impact on emergency admission rates and bed days, patient/carer experience and quality of life and the impact on Primary Care, and - using lessons learned - will help inform future mainstreaming of this activity.

The Caring with Confidence programme

In 2007, the Government announced its intention to invest £15 million in an 'expert carers' training programme, to be available, free, to unpaid carers. This programme is now in development, and is known as the *Caring with Confidence* programme.³⁶ It will be available to carers aged 18+ across England from June 2009, and is expected to provide support for a total of 37,000 carers in 2009-2011. Part of the Government's 'New Deal for Carers', and a significant element of the programme of support for carers announced in the new National Strategy for Carers launched in June 2008 (see page 14 in this report), the *Caring with Confidence* programme comprises a range of modules designed to help carers with various support needs (e.g. finance, practical care management, taking a break, accessing support and services). The modules will be delivered nationwide by selected providers in approximately 25 different sites around England. As part of the programme specification, online and self-study versions of the programme are also in development and these will also become available to carers during 2009; it is anticipated that about 10,000 carers will access the programme in this manner. The *Caring with Confidence* programme has a dedicated website providing details of the different options available. An online version, for carers to study in their own time, is also available.³⁷ Ensuring that carers from IEM communities are well represented among those carers taking advantage of all elements of the programme is a key objective for programme delivery, and among the providers delivering this support at local level, some are expected to be specialists in outreach and support for these groups.³⁸

ACE Radio

ACE Radio³⁹ was developed in Surrey, originally as Care Radio, and was a monthly audio resource for ACE partners, carers, employers, and those working with carers across the UK, Europe and internationally. It was developed as part of the Action For Carers and Employment partnership, funded in two phases (2002-5 and 2005-7) by the European Union EQUAL Community Initiative programme and led by Carers UK (Yeandle and Starr, 2007).

³⁶ <http://www.caringwithconfidence.net>

³⁷ <http://www.caringwithconfidence.net/online-sessions>

³⁸ The Department of Health has commissioned a full national evaluation of the *Caring with Confidence* programme from CIRCLE at the University of Leeds. This is in progress and due to report its full findings in June 2011.

³⁹ <http://www.carersworldradio.com/>

The ACE Radio programmes provided interviews and comment on the key ACE initiatives and policy developments, and were accessible via the internet from links on the ACE Radio, ACE National and Carers UK websites. The service was developed to offer podcasts of key broadcasts, live ‘streaming’ of major conferences and coverage of ACE national and transnational events.

Events from which broadcasts were made included: parliamentary receptions; launch events; and fringe meetings at the major party political conferences. Throughout ACE 2, ACE Radio regularly interviewed ACE partners, beneficiaries, stakeholders and key players across the UK and around the world. This innovative service was one of the first attempts in the world to support and inform carers using Podcast and related technology.

Forums and help-lines offering support to carers

A number of other UK-based organisations have also begun to explore technology as a way of conveying information to carers but also to encourage carers to share good practice via social networking and community engagement. Some of these are now well-established. The most common way that this has been put into practice has been through the development of online discussion forums and telephone help-lines.

The *Department of Health’s* official website hosts its own Carers’ Discussion Forum, intended to be a place for carers to exchange views and information. This website also has a separate limited access area to enable Carers Lead Officers (personnel with lead responsibility, in each CSSR, for developing local carers’ strategies and for implementing policy on support for carers) to come together to discuss existing and proposed care-related projects and to share ideas and information. It can be accessed at:

http://www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Carers/DH_079500

The national charity *Carers UK* has developed an interactive website which gives carers access to a wide range of resources to support them in their caring role. It also helps carers become involved in campaigning for change. The site includes resources for professionals working with carers and for policy makers, and information and booking facilities for Carers UK’s extensive Training and Consultancy Service. It is accessed by between 30,000 and 35,000 unique visitors each month. The website has a series of dedicated forums which carers can use to:

- network with other carers (to date it has covered approximately 4,000 topics, with 36,000 items posted);
- exchange information and offer support on specific disabilities and conditions (to date this has covered approximately 220 topics, with 1,200 items posted); and
- get involved in campaigning for change (to date this has covered approximately 470 topics, with 2,800 items posted)

These forums are moderated by nominated carers and Carers UK staff members, both to ensure that inappropriate material is not posted, and to help shape discussions. Carers UK sends monthly e-bulletins to all carers engaged in campaigning, and also has regular news items on the site.

Carers UK also administers the *Employers for Carers Forum*. This is a membership platform for employers who want to develop good workplace policies and practices to support working carers. It includes a range of web resources, including an online self-assessment benchmarking tool, and has online forum sections for employers and employees who are working carers, who can raise issues specific to them or engage in debate about particular topics.

A number of other online discussion forums and 'chat rooms' dedicated to carers' issues are now in existence too. These provide an opportunity for carers to exchange information and keep abreast of news related to carers. Some forums are more formal than others, being specifically used to address carers' issues (e.g. the Mencap forum: <http://www.mencap.org.uk/discussion.asp?id=2275>, which targets its support at carers of people with learning disabilities and mental health problems). Others encourage carers to discuss leisure activities and other everyday events in a more informal manner (e.g. The Family & Friends Carers forum: http://www.frg.org.uk/gpforum/forum.asp?FORUM_ID=3). A list of these and other discussion forums can be found in Appendix 1.

Carers' helplines

To support carers' need for accessible, comprehensive and reliable information to enable them to access services and support for themselves and the person they care for, the Government has established *Carers Direct*, an information service/helpline for carers. This service was one of the commitments made as part of the government's New Deal for Carers announced in 2007, and commenced in April 2009. Government is providing £2.8 million a year to fund the service, which is available as a telephone helpline 7 days a week, from 8 am – 9pm Monday to Friday and from 11am to 4pm at weekends. Carers can also email their queries. To make the service available to IEM carers, Carers Direct helpline uses a telephone translation and interpreting service, with access to more than 100 languages, and uses a three-way conferencing facility to enable helpline advisers to communicate with carers whose first language is not English. Advice on a range of topics of interest is offered to carers, including: assessments; benefits; Direct Payments; Individual Budgets; time off from work; and maintaining, leaving or going back to work, and the helpline aims to put carers in touch with local and specialist agencies where appropriate. Contact details: http://www.direct.gov.uk/en/D11/Directories/DG_10011166

Many voluntary organisations have also developed helplines for carers. These services provide information, support, guidance and referrals to other appropriate organisations. They are in most cases available from Monday to Friday during working hours (e.g. the Alzheimer's Society helpline:

<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200125>).

Some web pages detailing contact information also have online enquiry facilities so that carers can contact the organisation via a standard Internet network (e.g. the Age Concern helpline: <http://www.ageconcern.org.uk/AgeConcern/contactus.asp>).

A number of local authorities also offer a helpline to carers. These services are generally designed as a first 'port of call' for carers seeking information and sign-posting to services, or simply to provide someone to talk whenever this is required. The helplines are in most cases available from Monday to Friday and often operate during extended working hours into the evening (e.g. the Wigan and Leigh helpline: <http://www.carershelpline.co.uk/>). Many local authority helplines are linked to local social services application procedures, so that any information provided during a call can be shared with other departments in the local authority.

- <http://www.carershelpline.co.uk/>
- <http://www.norfolkcarershelpline.org.uk/>
- <http://www.bedfordshire.gov.uk/HealthAndSocialCare/Carers/BedfordshireCarersHelpline.aspx>

Web-based support for carers

In recent years, many local authorities have put in place web pages dedicated to promoting telecare options and facilities. [See Appendix 1 for a (by no means exhaustive) list of links.]

Box 9: Web-based support for carers

Example: Carers in Hertfordshire web pages (1)

The 'How can we help?' page on this website covers:

Informing carers of their rights.

How the local authority will spend time helping carers plan the support they need by problem solving and telling them about local services and specialist organisations that may support them.

Telling carers about ways they can look after their own health, meet other carers and add their voice to influence provision of services.

Contact details if carers are new to caring or have been a carer for many years, if they live with the person they care for or they live elsewhere.

Among the benefits of being in touch with Carers in Hertfordshire are:

- An opportunity to join an information mailing service and receive a copy of the local authority's countywide publication *Carewares* and newsletters four times a year.
- Help in planning the practical support that carers need in their caring role.
- An opportunity to request a planning support phone call.
- An opportunity for carers to get involved in discussions, listening events and consultations or to become a carer trainer.
- An opportunity for carers to acquire details of how to express their views and have a voice with other carers in the county.
- Carers can attend workshops and activities with other carers.
- All services are free of charge and confidential

Typically these web pages contain a mission statement emphasising the important role telecare can play in social care. There is also often a range of options available to both individuals (service users and their carers) and organisations (for example, housing associations or landlords). While these local authority telecare pages differ in terms of detailed content, the great majority provide information about who is eligible for telecare services, the kinds of telecare products available to users, and how to go about applying for these services. Some include frequently-asked-questions and answers, while others include PDF-style down-loadable documents, outlining the potential benefits of telecare equipment and explaining how it can impact on carers' lives and the lives of those they care for.

One example of interest is the local voluntary organisation *Carers in Hertfordshire*, set up in 1995. This aims to provide quality services to all carers throughout the county of Hertfordshire, and to do so in accordance with its Equal Opportunities policy. The organisation is governed by trustees, most of whom are carers themselves, and receives funding from a variety of sources, including the local authority (*Hertfordshire County Council*), which allocates some of its Carers Grant funds to third sector organisations supporting carers. Box 9 shows how the *Carers in Hertfordshire* website uses ICT to reach out to carers and offer them support. Another page on its website focuses on planning care support. We reproduce the web page's illustrative text verbatim in Box 10.

Box 10: Web-based support for carers
Example: Carers in Hertfordshire web pages (2)

The 'Planning the Support Carers Need' page covers:

- You may want help to continue in your caring role or support to make the choice to change or stop your caring. Talking through what you want may help you to decide what to do next.
- Your caring may leave you little time for yourself and your own well-being may be affected. We can find ways to help you have time away from your caring responsibilities to rest, pursue your own interests, spend time with friends or have a holiday.
- If you are worried about the cost of caring, ask us to arrange a benefits check to find out whether you and the person you care for is entitled to any financial support or seek out potential funding for a holiday, equipment or extra support.
- Caring may affect your own health. We can help you to lessen your anxiety, stress and isolation with information, for example, about relaxation or lifting skills and encouragement to take part in activities.
- You may be considering giving up or taking employment – we can ensure that you know your rights as an employee and explore the options open to you as a working carer. We can help you assess the impact of any work-related decisions and find out what services are available for the person you care for.

Contact us via email or through your local office to request a planning support phone call.

As this second part of the report has demonstrated, our literature review and the policy initiatives we have studied indicate that in the UK, there have in recent years been a number of important developments in the way ICT is used to support and enhance the provision of services across the social care system, affecting a wide range of public, private and voluntary sector agencies.

In Part 3 of the report, which follows, we look in more detail at a number of projects, schemes and developments, presenting these as a series of case studies to illustrate some of the very different ways in which these have offered new and different services and support to carers and care workers. The evidence presented in the eight case studies we have included was collected mainly from the organisations concerned, and draws on documents which they supplied, telephone interviews with key organisational personnel, and information presented on their websites. In some cases, these sources were also supplemented with a face-to-face meeting or a visit to the agency concerned.

3. ICT developments supporting carers and care workers: case studies

Introduction

A web search of organisations in the UK dedicated to telecare activities revealed a number of information services, advice centres, knowledge networks and product manufacture/provision groups. These web-based resources generally provide information to service users, professionals and suppliers. Product manufacturers typically provide information about existing equipment and future research into new telecare equipment products and services. Other organisations detail how service users can go about accessing telecare equipment, often indicating some of the costs involved, how telecare equipment can interact with existing services (such as Direct Payments), and other potentially useful information. Regular newsletters are available for download on some web-based resource pages, while case studies illustrating the benefits of telecare can sometimes be found on other web pages. One organisation (Tunstall – see below) provides an online training tool designed to help professionals become more skilled in providing appropriate telecare packages to service users. A list of web links to many of these organisations can be found in Appendix 1.

Eight of these organisations are presented here as more detailed case studies, to illustrate some of the scope, variety and potential of ICT-based initiatives supporting carers and care workers. Our selection includes manufacturers of ICT equipment, charities, local authorities, and educational institutions.

Case study methodology

The case studies were conducted through website reviews, telephone interviews and documentary analysis. The website reviews sought to identify key documents and descriptions relating to existing schemes and projects currently being implemented by organisations in the field of social care. This data was examined for its relevance to the aims of the current project – the potential for ICT initiatives to support and engage carers and care workers (including IEM groups) – and where organisations appeared to be doing interesting work in this area, a telephone interview (or meeting) was sought with a key member of staff.

The telephone interview schedule (see Appendix 5) was designed to elicit more detailed information than the organisation's website could provide by asking a number of questions focused on carers, care workers and IEM groups: what facilities had been developed to support these groups, when these were established and what the source of funding was; how users were monitored; how the facilities were promoted; how the facilities connected up with other services offered by the organisation; and how the facilities featured in future plans.

This approach elicited a great deal of material about ICT initiatives. What follows is a discussion of key features of these schemes, which form part of the total social care system supporting carers and care workers.

How ICT and telecare is used to support for carers and care workers

Our case studies illustrate some of the ICT initiatives currently being developed and implemented in the UK. They were selected to demonstrate different ways in which ICT-based schemes are being used to support and engage carers and care workers, as well as some of their limitations and any barriers they face. The case studies reveal that although some organisations have identified ICT as an important way of providing care-related services, others have as yet made only limited use of ICT, and require more explicit guidance on how ICT can benefit their clients, and on how they could use ICT to expand, enhance and develop the services they are already providing.

The first case study presented features one of the world's leading developers and providers of telecare products. *Tunstall*⁴⁰ has developed, manufactured and installed a growing range of telecare products designed to help frail, sick or disabled people live safely and independently at home. Its approach highlights the benefits of telecare for carers, promotes telecare installations as a means of reducing unnecessary health and social care costs, and offers support, training and information about its products to carers, domiciliary care agencies, local authorities and others, using ICT as a prime means of conveying this material.

⁴⁰ Trading in the UK as *Tunstall Healthcare Group Ltd*, in 2009 Tunstall also had business operations in; Europe - Belgium, France, Germany, the Netherlands, Portugal, Spain, the Nordic region and Turkey; in Australia and New Zealand; in Canada and the USA; and in Malaysia, Singapore and Taiwan.

Case study 1: Tunstall - telecare solutions manufacturer and supplier

Established in 1957, Tunstall considers itself to be “the world’s leading provider of telecare and telehealth solutions.” Based in the north of England, the company operates in 30 countries, supporting 2.5 million people through the world, by:

- Developing world leading telecare technology.
- Offering support, via a network of 160 engineers nationwide (UK), backed up by a 24-hour customer satisfaction centre.
- Investing in research and development.
- Providing certified facilities.

Tunstall is a founder member of the **Continua Health Alliance** (a non-profit, open industry alliance of the finest healthcare and technology companies in the world, whose members have joined together to improve the quality of personal healthcare).

Tunstall manufactures a wide variety of telecare / telehealth solutions:

- Telecare home units
- Telecare sensors
- Telehealth solutions
- Telehealth monitoring software
- Activities of daily living solutions
- Environmental control solutions
- Mobile alarms
- Telecare home unit accessories / packages
- Accessories for telecare

Tunstall’s website offers a range of customer support facilities including advice on dementia, falls, intermediate care and learning disabilities, as well as telecare solutions for each condition based on the available equipment. There are also video- and audio interview-based case studies available to download. Its website also hosts a **Telehealthcare Support Group** which has dedicated web pages available to customers via a log-in system.

It has also developed a series of regular “**webinars**” (Internet/telephone based seminars) that allow customers to listen to a presentation and then engage in a question and answer session at the end.

A **Telehealth Online Resource Centre** was recently launched via its website, designed to offer to telehealth customers (including carers) resources such as case studies, information on installation of equipment, details concerning engineer support, downloadable instruction booklets and return procedures.

For professionals, there is also a password-enabled **online Telecare Training Tool** that allows care workers to engage with a number of virtual care assessment scenarios and to participate in role-playing as a way of gaining knowledge, experience and confidence in prescribing the kind of telecare packages that would be suitable for a client in each case.

Tunstall is currently providing technology and equipment in the three **Whole Systems Demonstrator (WSD) trials**, which aim to find out if integrating health and social care using new technology can help people keep well at home. The demonstrator sites aim to provide information about “the extent to which integrated health and social care supported by appropriate technologies can promote individuals’ long term well-being and independence, improve quality of life for them and their carers, improve the working lives of health and social care professionals, and provide an evidence base for more cost effective and clinically effective ways of managing long term conditions.” The three WSD trials started in June 2007 and run until March 2010.

As shown above, Tunstall is a company at the leading edge of technological development in health and social care. It is the major supplier of telecare equipment to local authorities in the UK, holding supplier contracts, agreed via local commissioning arrangements, to provide telecare equipment and support in most. Among its clients is Nottingham County Council, whose telecare project is the second of our case studies.

Nottingham County Council's telecare project is an example of an English CSSR building telecare expertise and capacity, pump-primed by the Department of Health's *Preventive Technology Grant*. As shown, it has identified IEM carers and service users as a group particularly likely to benefit from telecare support, and is tackling barriers to the efficient and effective use of telecare, using on-line training and computer-based guidance for staff, users and carers. This example highlights both opportunities and challenges facing local authorities aiming to use ICT to offer improved support to users and carers. .

Case study 2: Nottingham City Council's telecare project

This telecare project is one of a number of examples of what local authorities in the UK offer carers in the form of ICT-based initiatives. A range of telecare sensors (provided by Tunstall – see above) is available to people over the age of 65 and to disabled people aged 18+, who have been judged, in a community care assessment conducted by a social worker, occupational therapist or home care worker, to have suitable support needs. The installation of sensors, etc, is free of charge, although a small weekly charge is made to cover monitoring costs. This project has been developed using funds available from the Preventative Technology Grant as well as resources from some other local authority budgets. It is promoted in the region via carers' events, Day Care Centres, local media, council newsletters, a short video, display stands at libraries, the Internet, GP and health surgeries and via social care staff. Immigrant and ethnic minority carers have been targeted via literature translated into relevant languages. Although no formal evaluation of the project has been conducted, anecdotal feedback from carers is reported as 'very positive'. Our interviewee based in Nottingham County Council reported that staff also viewed telecare as an important part of present and future healthcare packages, although he emphasised that telecare was not regarded as a replacement for more traditional 'face to face' care services.

For its own social healthcare staff, Nottingham County Council makes extensive use of Tunstall's online training tool (see case study above for details) to enable them to learn how to assess carers' ICT needs effectively. In-house training is also offered, including guidance on how to use a computer-based intra-net system as a source of information with newsletters, frequently-asked-question lists and blogs by other members of staff (regarded locally as a good way of sharing experience).

One barrier to effective use of these technologies is a lack of co-ordination between the different IT systems used in social care and health. The local authority has been considering harmonising these systems to enable all staff to access the same information. It was also noted that some members of staff have been reluctant to use IT equipment, because they lack knowledge and confidence. To address this, refresher training is offered regularly to encourage staff to remain mindful of the potential of ICT in social care,

While telecare/telehealth equipment is now on the agenda of Nottingham City Council and many other CSSRs, initiatives using ICT to support and engage carers - via social networking, or using ICT to provide them, or paid domiciliary care workers, with training and support/advice - are in an early stage of development. In Nottingham, this was partly because of a lack of staff knowledge and confidence about the way ICT might be used, but was also associated with limitations in existing ICT-based facilities at the local authority. As revealed in other studies (and discussed in the previous chapter) a lack of knowledge of existing technology is a well-documented barrier to ICT development in social care.

Nevertheless some local authorities have, alongside their more conventional telecare provision, developed ICT-based initiatives aimed specifically at using technology to support

carers. One such project was Leicestershire City Council's telephone befriending service, another of our selected case studies. This scheme uses the telephone to connect carers, both to combat the isolation and social exclusion carers often experience as a consequence of their caring role, and to help them access information, guidance and support. This simple scheme offers a low-cost way of providing mentoring and support to carers, and scheme staff are currently considering ways in which it could be further developed using other ICTs.

Case study 3: Leicestershire County Council's Telephone Befriending Scheme

This scheme has been in place for two years. It originated as a pilot scheme funded through the council's Carers Grant allocation, but has now been 'mainstreamed' and is resourced using its main social care budget. It was developed to meet the needs of carers in the region who require help, advice and reassurance relating to any social care issue. The scheme is run by volunteer telephonists (often carers themselves) who provide signposting to other services offered by the local authority; all volunteers are equipped with useful telephone numbers and contact details of Carers Project Workers and other key members of staff. The carers who use the service tend to be older people who have demanding caring roles. All calls are logged by the volunteers. The scheme has been approved as a mentoring scheme via the nationally recognised quality assurance body.

The manager of this scheme reported that it had proved very popular with carers who used it (their numbers were not known). The scheme is promoted and publicised through a range of local activities (such as those linked to 'Carers Rights Day'⁴¹) and through voluntary organisations and public venue using leaflets, posters, etc. Recently Leicestershire County Council has been considering expanding the scheme to reach out and engage IEM carers, although it is thought additional funding will be needed for this, as difficulties are anticipated in identifying volunteers who speak different languages.

The project manager believed it would be useful to explore others ways of using ICT to reach carers. She noted that although newsletters are already offered by email, many carers registered with the council are older people providing high levels of care and that few carers in this group chose to receive the newsletter in electronic format. A recent evaluation of care-related services, conducted with 300 carers and using a questionnaire available in both paper and electronic versions had elicited 120 responses, only 6 of which sent via email. Her perception was that more funding would be necessary to explore additional ICT-based initiatives, and share knowledge about its possibilities. She emphasised that ICT was not seen as ever 'replacing' traditional 'face-to-face' services, but that she hoped it could play a major role in future provision of social care by reducing service costs and increasing the effectiveness of services.

This befriending scheme offers a good example of how very basic ICT-based equipment – in this case, the telephone – can be developed as a service to support and engage carers. Other local authorities are engaged in other ICT-related projects, including the use of computers to provide online forms for carers' assessments. As indicated in the Part 2, some organisations also make use of online forums to allow carers and care workers to exchange information via Internet-hosted discussion groups.

One such forum is hosted by *Carers UK*, and in Case Study 4 we highlight how the national charity *Carers UK* supports carers in all parts of the country via its online discussion forum. This is just one of a wide range of ways in which, developed over its 40-year history, *Carers UK* makes its free services available to the UK's population of carers. Other support currently offered includes a telephone helpline, and an extensive, regularly updated website. The website contains high quality information on carers' rights and entitlements and on policy and practice developments, debates and initiatives. The online discussion forum featured as

⁴¹ Carers Right Day is a well-established, annual, voluntary-sector led initiative, featuring both national and local events designed to raise awareness of carers' issues and to promote new policy initiatives and campaigns.

Case Study 4 is a recent, successful innovation, which is cost-effective and valued by users, showing how ICT-based social networking technology can be used to benefit and support carers.

Case study 4: Carers UK's Online Discussion Forum

This project has become the UK's most popular online discussion group specifically aimed at carers. The following information was provided by one of its moderators:

Since 2005, Carers UK has helped carers break isolation by providing an online forum which puts carers in touch with each other, offering peer to peer support, information and a listening ear. The forum has seen a remarkable period of growth, meeting a real need. Crucial to its success has been the central role played by carers who run the forum. The project meets our strategic aim which is to provide support and advice to carers and carers involvement.

Currently we have:

- 2 carer volunteer moderators
- 2 staff at Carers UK who help moderate as part of their wider duties
- 1500 members on the forum of whom 875 have posted a message

We also know that the forum is viewed more than any other part of the website by approximately 30,000 people each month who do not necessarily post a message. In terms of our growth in 2008 we recruited on average 59 new members each month.

Forum membership table

Activity	Number of forum members	% of membership*
1-10 posts	645	43
11-50 posts	135	9
51-300 posts	70	5
More than 300	25	2
Never posted	625	42
Total	1500	100

* Figures do not add to 100 because of rounding

This shows us that most people who join are 'lurkers'. They either view and don't post, or make a small numbers of posts usually to ask direct advice to a specific problem, then they drop out. We know anecdotally, that as in any other social situation, some carers can find it a little intimidating taking their first steps into this virtual community. Our moderators know this and take time to welcome and nurture new people.

Aside from those who sign up and join the forum we know it also has a large readership who simply visit to read the posts. Each month our website averages 30,000 unique visitors, with around 850,000 page views. Of these page views the Forum is the most popular. Our main Carers UK home page gets about 40,000 page views. The forum home page gets 66,000. Carers tell us they want to access information from people like them who know what they are going through.

Examples of posts from the forum:

Frandrake. Joined: 01 Nov 2008. Posts: 236. Location: North Shropshire

We always think that we're the 'only' ones, don't we? Because we don't get the chance most of the time to talk to other carers much about these things. Shows just how good Carers UK really is, putting us in touch with one another, to share stuff. Carers UK is the best site I've been on for carers. It's got the friendliest members I've ever seen. The support I've had from this site has been second to none.

Pete the Paint. Joined: 24 Apr 2008. Posts: 560. Location: Devon.

I love this site. It gives me much more than I could ever give back. I never cease to be amazed at the kindness and generosity of the wonderful Carers who post here. I don't know what I would do without this fantastic site, or the kind Caring folk on here.

Pixienubbins. Joined: 25 Aug 2007. Posts: 839. Location: Dorking, Surrey

This forum is most probably the best gift a carer can have we come on to support each other,, make sure every one is doing as well as they can and if not offer them an ear, pm (private message) or hug this forum is what's keeping me going lol,, I'd be completely insane otherwise.

Ace. Joined: 18 Feb 2009. Posts: 25. Location: London

Many thanks to you all. I'm amazed by the number of informative and helpful threads on here. it's so much more useful hearing peoples real experiences with the problems of caring than trying to work your way through official sites full of unintelligible gobbledegook. I'm learning so much from your site. In the short time I've been here, the kindness and support shown to me has given me much strength.

Tiredn stressed. Joined: 10 Feb 2009. Posts: 15. Location: United Kingdom

Every time I've posted and felt totally desolate, I've been cheered up and feel like I've got an army of neighbours around me if I feel bad. Your support has helped no end.

An interview with this moderator also revealed the following issues:

- It was thought that the most frequent user of the Forum was in her or his 40s, though there were also a number of older members. The youngest member was approximately 20 years old. The average age of Forum users was thought to be lower than that of carers registered at Carers UK.
- Although carers across the world have access to the Forum, the overwhelming majority of users were thought to be located in the UK. Moderators estimated that most carers using the Forum were white, working-class and not currently in paid employment. It was thought that very few IEM users had registered as Forum members (although it should be noted that ethnicity data is not collected and that this view is based on assessment of the content of users' posts).
- There is a wide range of carers of people with different conditions among the Forum's membership. The 'virtual' environment was thought to eliminate differences between these groups (policy differences relating to conditions, etc.) by allowing them to focus on common issues (e.g. the practical difficulties of caring).
- There has been some discussion at Carers UK concerning whether membership of the forum – which is currently anonymous – should be made more formal by requesting users' real names. This was thought to have advantages and disadvantages. In the first case, it would protect users from harassment and bullying by occasionally abusive members. In the second case, this was felt to endanger the anonymity involved in the forum, an attraction thought to be valued by carers seeking the "comfort, trust and community" of a "virtual family".
- Experience had taught the Forum team that it was important to adopt a "zero-tolerance" attitude towards people who violated the "supportive environment" the Forum was designed to provide.
- Private messaging was facilitated by the Forum's technology and carers made extensive use of this. These messages could not be moderated, and some difficulties in dealing with abuse between members conducted via this more private method had been encountered.
- Several carers involved in the Forum were known to have met each other (in public) as a consequence of their membership. One couple who met on the Forum eventually married each other!
- A few years ago the Forum had been expanded to include care workers. This development was viewed as very unsuccessful and had been abandoned, because once carers became aware that a Forum user was a care worker, they "attacked" them, complaining about the quality of carer services. It was noted that another online forum (developed by different carers' organisation, with the intention of bringing carers together with care workers) had experienced similar difficulties. Carers UK had no plans to redesign a forum for care workers in the future.
- Carers UK hopes to attract future funding to expand the number of moderators to 10 or 15 and to provide enhanced training for them, in the form of a manual. It was noted that it is important for moderators to know how to handle difficult situations; for example, on one occasion a moderator had received a private message from a carer threatening to kill himself. Carers UK would like to promote the Forum more widely, and to consider the use of Internet chat-rooms, which allow users to chat together more quickly. However, there are a range of difficulties (relating to moderation, etc.) which required careful planning, and this service is not yet available.

As can be seen, Carers UK's forum has proved a particularly successful way of engaging and supporting carers via ICT technology other than telecare/telehealth equipment. Further innovative uses of ICT have been developed by other organisations in the UK, including facilities designed during a major nationwide project aimed at supporting and engaging people with learning difficulties. We have selected the TATE project as one of our case studies as an innovative project set up with significant resources.⁴²

⁴² The TATE project has been more fully reported elsewhere: see Beyer et al (2008a) and Beyer et al (2008b).

Working in partnership with the *Foundation for Assistive Technologies*, TATE, the fifth of our case studies, has demonstrated how ICT can be used to support people with learning difficulties and their carers, both through web-based support and training and through telecare solutions in their homes, to help in the management of risks and challenges in their everyday lives.

Case study 5: TATE - Through Assistive Technology to Employment

TATE operated from 2004 until 2008 across England and offered a wide range of registered residential services and supported living initiatives. A group of 14 organisations working in partnership, it focused on investigating the role of assistive technology (AT) in supporting service users and staff. The core belief was that AT has a crucial role to play in empowering individuals and enhancing the employability of people with learning disabilities (LD) and their carers.

TATE's stated objectives were:

- Demonstrating how AT can support independent living for LD and their carers, thereby increasing their employability and allowing them to take a full and active part in the communities in which they live.
- Involving LD and their carers in the design, implementation and delivery of AT systems within a variety of living environments.
- Developing life skills software to enable LD and their carers to develop the full range of life skills necessary to improve their skills in key areas, e.g. money management, thereby enhancing their employability.

TATE's objectives were achieved via the following procedures:

- Identifying current barriers to the effective implementation of AT for people with LD and their carers
- Developing an assessment tool for people with LD and their carers to enable the effective use of AT within their living environment. The tool has been jointly developed by housing provider staff and beneficiaries.
- Developing and accrediting training for people with LD and their carers to enable them to implement AT within various living environments. The training package is being accredited by City & Guilds.
- Testing various AT systems in different housing environments. Housing and care providers will provide suitable sites for the development and testing of AT identified
- the full involvement of beneficiaries in the design, implementation, delivery and evaluation of the AT systems
- Developing and testing a life skills software package designed and tested by people with LD and their carers. Software houses, e.g. Granada Learning, have been developing this in consultation with beneficiaries.
- Development of an existing web site on AT for people with LD and people who work with people with LD. FAST (Foundation for Assistive Technologies) has been undertaking this work throughout the lifetime of this partnership.

One of TATE's original partner organisations was HFT (Home Farm Trust), a charity which since 2008 has developed much of the work the TATE project began. In Case Study 6, we highlight how this organisation uses ICT in its social care initiatives and activities.

Case study 6: HFT - Home Farm Trust

HFT is a national charity providing long-term support for people with learning disabilities and their families. It offers a wide range of flexible and creative services throughout the UK for over 1,000 people, including assistive technologies. In 2004, the organisation secured funding from the European Social Fund to lead the TATE project (Through Assistive Technology to Employment), which aimed to use assistive technologies that were traditionally associated with the care of older people for people with learning difficulties. The TATE project ended in 2008, but HFT continues to implement assistive technologies to its clients.

HFT has developed a needs-led assessment process for introducing its clients to assistive technology. This process evaluates every stage of the procedure: referral, consent, assessment, funding, equipment identification and ordering, response protocol, installation, review and changing needs. All these stages include a focus on the families of the client.

HFT also runs the Karten CTEC Centre. This implements the use of ICT in many innovative ways, including staff training on computers to meet the needs of HFT's client base. The CTEC Centre has 18 computers with broadband networks, an interactive whiteboard, data projector and up-to-date software. Additionally, the CTEC Centre runs a variety of ICT-based courses for clients, the most popular of which is a one-day life-story workshop designed to allow clients to put together a multimedia profile using computer technology. There are also courses that use email with specially adapted symbols for use by people with learning difficulties. These courses are accredited by City and Guilds and the Learning Disability Awards Framework.

An interviewee at HFT reported that while their various schemes have not been formally evaluated, 'word of mouth' feedback has been very encouraging. Carers find that ICT facilities such as email alleviate social exclusion, allowing them to maintain contact with family and friends. Despite some concerns from clients in the early stages, demonstration of the ICT-based courses reveals their benefits and overcomes initial fears.

For care workers, HFT provides a number of basic training packages for email, Internet searching and multi-media programmes. The organisation employs five trainers with ICT expertise. HFT also hosts an intra-net based exchange forum that has around 500 professional users (a satisfaction survey was recently conducted). The organisation is working towards enabling all staff associated with it to communicate via the Internet. However formal courses are not provided as experience has taught that staff would not attend them. Engaging care workers with ICT-based facilities was viewed as 'a constant

challenge', as this approach is not yet part of the core requirements made by regulators and key agencies, such as Skills For Care. Funding has been hard to secure, with a reliance on grants (including one from Vodafone). In the future, HFT hopes to develop e-learning facilities and online modules for training purposes, and to have all staff able to use ICT-based services by 2012.

HFT has experienced some difficulties in developing work with IEM carers and care workers. Different ethnic groups are recognised as having different needs in relation to care, with some groups' understanding of disability different from that of traditional services. HFT has started to look into how ICT-based facilities can be adapted to provide support for IEM groups, but work was at a very early stage. One practical aspect of this is the need to have computer keyboards sensitive to different languages and alphabets.

The interviewee at HFT emphasised that it is important to see ICT-based facilities as a way of helping to deliver services, and not in any way as a replacement for traditional services.

HFT's projects used more complex ICT-based equipment than has so far been developed in most local authorities. Its schemes were predominantly aimed at service users and care workers.

City and Guilds, mentioned in Case Study 5 as the organisation which accredits TATE's training for people with LD and their carers, developed the UK's first ICT-based training programme specifically for carers, and offers support and engagement for both carers and care workers through ICT applications. Its achievements in this area are presented in Case Study 7.

Case study 7: City and Guilds – ‘Learning for Living’ and ‘SmartScreen’

City and Guilds is “the leading provider of vocational qualifications in the UK.” Its qualifications assess knowledge, understanding and skills that are of real value in work, life and leisure. These qualifications are recognised worldwide for their quality. City and Guilds provides a number of IT-related courses and facilities for both carers and care workers.

Learning For Living is an Internet-based training course designed to provide carers with the skills and knowledge they need in their everyday caring roles.⁴³ Successful completion of this course results in a formal qualification called ‘Certificate in Personal Development and Learning for Unpaid Carers’. Carers with access to a computer are given a username and password to log on to the online resources available at www.learning-for-living.co.uk. Here they study four modules:

- *Moving forward*: involves help on returning to study, coping with complexity in life and planning for the future.
- *Taking care*: involves keeping healthy and enjoying life.
- *Living with others*: involves understanding relationships and coping with loss.
- *Managing as a carer*: involves money management, safety matters and understanding care services.

The modules are delivered via a range of online tests and quizzes involving typing in appropriate answers and completing drop-down multiple-choice questions. There are also useful DVD-style video- and audio recordings to help carers with the course. Tutors are additionally available via email to provide instruction and feedback. There is also a helpline linked to the course for technical assistance.

The course is funded and delivered by affiliate organisations such as local authorities and colleges. These organisations recruit carers to the course and offer a face-to-face introductory session to help carers who may lack appropriate IT skills. An interview with one of the people who developed the course revealed that the course generally relies on a suitable ‘champion’ on its behalf and that a shortage of funding for carers often renders it difficult to roll out the course in as ambitious a manner as would be preferred. Nevertheless since 2004 approximately 700 carers have engaged in the course. Future plans involve updating it to cover more recent carer policy developments such as Direct Payments.

For care workers, City and Guilds has two significant projects related to ICT and care. The first is an accredited course for care workers to learn how to assign appropriate telecare packages to clients in needs of them. The course, called the Certificate in Supporting the Users of Assistive Technology, is in a very early stage of development, and so far has had little take-up. This was attributed to the fact that telecare projects have yet to be mainstreamed in the career market for care workers, with such qualifications often regarded as “luxuries” rather than essential. Nevertheless City and Guilds is committed to delivering this course and has high hopes for its future.

The second project is an online facility called SmartScreen (www.smartscreen.co.uk). This allows City and Guilds tutors and learners alike to access a range of resources relating to their courses. SmartScreen offers a range of user-friendly downloadable documents, video- and audio-recordings, quizzes and tests, etc. There are also forums for tutors to discuss issues relating to courses, and all learners have online access to their tutors via email. Formal assessments can be submitted and/or completed online via SmartScreen, too. Tutors and learners working on social care qualification have full access to the system. SmartScreen has become very popular and widely-used since its inception in 2003 (there are now approximately 47,000 registered users of SmartScreen at City and Guilds) and other organisations can buy an annual licence to enable it to support their own service provision. 2000 other organisations presently make use of the system. City and Guilds has not developed any courses or facilities to specifically address IEM carers and care workers, although diversity issues are well integrated in its existing courses.

⁴³ *Learning for Living* was originally developed as part of the ESF-funded *Action for Carers & Employment* (ACE) project led by Carers UK, during its first phase, 2002-5 (Yeandle and Starr 2007).

As we have shown, both HFT and *City and Guilds* draw enthusiastically on cutting edge technologies to support and engage carers and care workers, as well as those they care for. However our enquiries with representatives of Case Studies 1-7 and our expert interviews with other organisations yielded very little information about ICT support for IEM carers and IEM care workers. We therefore targeted an organisation whose explicit focus was ethnic minority groups in the field of social care, the *National Black Carers and Carers' Workers Network*, to explore its role and knowledge of developments in this area, and the information it provided is presented in the last of our case studies, Case Study 8.

Case study 8: National Black Carers and Carers' Workers Network

The National Black Carers and Carers' Workers Network (NBCCWN) is facilitated by the Afiya Trust, whose purpose is to work towards reducing inequalities in health for racialised groups in the UK. The NBCCWN is a network for carers and carers support workers. In 2002 it published a major report called *We Care Too: A Good Practice for People Working with Black Carers*, and in 2008 a supplement to the original report called *Beyond We Care Too, Putting Black Carers in the Picture*.

Among the issues related to telecare developments discussed in these reports are the following:

- People from different communities require culturally sensitive ways of accessing the services they require, and some services may need to adapt the way their services are provided appropriately.
- Services for IEM communities are often set up on a time-limited project basis and are not always properly evaluated. As a result these projects are often vulnerable when funding ends. Such projects need to be planned with a view to mainstreaming.
- It is important that services target hard to reach communities and that they are properly monitored. If services can be demonstrated to provide improved health, they are more likely to be sustainable.

An interview with the leader of this network revealed that, in her experience, many carers with IEM backgrounds lack knowledge and skills relating to ICT. There were also thought to be major barriers to overcome relating to different languages in any scheme involving the use of ICT. For these reasons the NBCCWN has always regarded ICT-based issues as a "secondary consideration".

Responding to enquiries made in the study reported here, our interviewee indicated that although she believed a group of IEM carers who cannot be reached via ICT-based initiatives will remain (largely on account of their lack of ICT-related knowledge) NBCCWN would be receptive to advice and guidance on how ICT and related technologies might help support and engage carers linked to the organisation. Currently, however, a shortage of funding did not permit the Network to prioritise work in this field.

Thus although the NBCCWN is eager to engage in ICT-based initiatives to develop its work with IEM groups in the field of social care, a lack of knowledge about which technologies might be useful, and of resources to develop suitable projects and programmes, have hitherto hindered any research and/or project development in this area.

Overview of case studies

Using a range of case studies, in this part of the report we have drawn attention to some of the ICT-based initiatives which have been developed in England and the UK in the field of social care. Our enquiries have revealed a number of organisations which are embracing and developing new technologies, seeing them as offering considerable scope to offer improved support to carers and care workers operating in domiciliary care environments. Others have shown that they are eager to discover how ICT could be further developed to support and engage with the carers, care workers and service users linked to their existing services.

As we have indicated, England contains some organisations which have led the way in identifying and developing ICT support and telecare for users, carers and care workers. These include *Tunstall*, a world leader in social care ICT applications, already having considerable impact worldwide as it rolls out its technological developments to partners and clients. *Tunstall* already has contracts and partnerships within the UK in England, Scotland and Wales. These are actively supporting local authorities to implement their strategic aims in this field - namely, to use ICT and telecare to improve service user experience, enable more people to live independently at home, and support carers of frail or disabled older people, of people with learning difficulties and carers of people with certain conditions (e.g. epilepsy) to manage their caring role with reduced stress and anxiety. As an organisation *Tunstall* is also highly attuned to the importance of using ICT and telecare to reduce costs in the social care system through the preventative role of technology, and is already operating on a global scale.

Other organisations featured in our case studies (*Carers UK, HFT and City and Guilds*) are already using some of the sophisticated equipment and IT applications now on the market in new and innovative ways. Others (including the local authorities featured) view ICT as an important element of the future social care system, yet at this stage lack the necessary resources, knowledge or expertise needed to implement fully operational ICT systems and applications across all their social care services to suit the needs of their full range of clients and staff.

Our enquiries (as discussed further in the Part 4 of this report) show that the role of ICT in supporting and engaging IEM groups in social care system – whether as carers providing unpaid support to family or friends, or as care workers employed in the domiciliary care system, is under-developed. This suggests that this is an area ripe for exploration and further development, both via agencies which specifically target the IEM community (such as the *NBCCWN* and the UK's many local community groups which work to meet the needs of IEM communities) and through mainstream social care agencies and providers, as a means of enacting their responsibility to provide services across the diversity spectrum.

In the final part of this report, we turn to the limited evidence available about carers and care workers in IEM communities in England and the UK.

4. Immigrant and ethnic minority carers and care workers and ICT

Our study and literature searches revealed only limited evidence of projects or programmes designed specifically to support IEM carers, or to assist IEM care workers providing domiciliary care. Nevertheless, we can note evidence that:

- People in some ethnic minority groups are particularly likely to have caring responsibilities (in part because of a higher incidence of illness and disability in some IEM communities, which tend to be concentrated in areas of socio-economic deprivation).
- Black and minority ethnic carers are not well represented among carers accessing services (in either the statutory or voluntary sector), a fact recognised by many agencies and by central government, which has identified them as a group to be targeted in some programmes and projects (including the national *Caring with Confidence Programme*).
- Some ethnic minority groups (notably the Black African and Black Caribbean groups) are relatively highly concentrated in paid care work, including domiciliary care.
- The social care sector has a tradition of recruiting migrant labour from outside the UK.
- Workers employed in private households are disproportionately drawn from foreign migrant workers.
- Foreign migrant workers and workers from some resident ethnic minority communities face particular challenges of communication, especially when newly arrived in the UK, and need additional and different support, information and opportunities, to network, exchange experiences, and gain understanding of the social care system and how it works.

The importance of this topic is demonstrated in a recent report (Salt and Millar, 2006) which analysed patterns and trends in foreign labour in the UK. Using official data, this demonstrated the upward trend in the number of foreign nationals living in the UK (1994-2005), with 45% of the UK's 1.5m strong foreign workforce coming from other European countries in 2005. The report showed that about two-thirds of foreign workers live in London and the South East (compared with only 31% of UK nationals). The study, which included analysis of work permits issued in 1995, 2000 and 2005, showed significant fluctuations in the countries from which foreign workers come to the UK. In 2005, about one third of work permits were issued to people coming from India (compared with only 8% in 1995), but while the percentage of permits issued to workers from the Philippines had risen sharply (to 10.5%) in 2000, this figure dropped back to under 6% in 2005. A particularly important trend, in the context of this study, was that the proportion of permits issued to workers in the health and medical services industry had risen sharply, from 7% in 1995 to 22.5% in 2000, reaching 26.1% in 2005. In 2005 alone, over 17,000 work permits were issued to 'nurses and carers', while 1,348 were issued to 'care assistants and home carers'.

Salt and Millar's analysis of the countries from which specific groups of economic migrants came indicates that (between 2000 and 2004) workers in the 'caring personal service occupations' came primarily from the Philippines, India and Pakistan, with smaller numbers recorded coming from Romania, South Africa, Australia and some other countries. The pattern of work-based migration to the UK is complex (with a variety of legitimate routes available⁴⁴) and subject to policy change. A recent investigation of Central and East European migrants in low wage employment (Anderson et al 2006) highlighted a range of

⁴⁴ Schemes (and the number of cases recorded in 2005) include the 'Worker Registration Scheme' (195,000), 'Work Permits' (86,000), the Highly Skilled Migrant programme (18,000); domestic servants (10,000); au pairs (2,300); the Seasonal Agricultural Workers Scheme' (15,000), among others [all figures rounded]. In addition, over 35,000 entries were recorded in 2005 from the 'EU and EFTA'.

issues for this group, noting that ‘recruitment methods had changed after EU enlargement. Direct recruitment, use of migrant networks, and the use of the Internet had reduced dependence upon agencies’ (p4).

A specific study of immigration in the social care sector was recently undertaken for the UK’s *Migration Advisory Committee*⁴⁵ (Moriarty et al 2008). This noted ‘strong demand for labour’ in the sector as a ‘way of dealing with recruitment problems in social care’, and evidence of increased recruitment from the European Economic Area (EEA), especially Poland (although doubts were expressed about how long EEA workers would remain in the UK). Citing other evidence (Experian 2007) based on the Annual Population Survey 2006, this study noted that 16% of the UK’s 640,686 workers employed as care assistants and home carers (some of whom work in residential care) were born outside the UK. In London, this figure was far higher, at 68%. The report pointed out that employers face a number of challenges in recruiting domiciliary care workers, and that a recent study (Evans 2006) had concluded: ‘existing knowledge about international recruitment of social care staff is inadequate for planning purposes’ (Moriarty et al 2008; p 26). Nevertheless the somewhat patchy official data available indicates:

- Labour Force Survey data (analysed by Spence 2005) found that in London, workers from Jamaica, Nigeria, Ghana, Mauritius and the Philippines were all over-represented in health and social care occupations.
- Analysis of the UK Worker Registration Scheme (affecting the EU Accession countries, the A8) shows that between May 2004 and September 2006, over 14,000 workers from A8 countries were working as care assistants and home carers.
- In 2003-4, almost 25,000 work permits were granted to ‘senior carers’; almost 5,000 of these were granted to migrants from the Philippines.
- Although migrant workers were often well (or over-) qualified, and frequently regarded as ‘hardworking’ and adaptable, ‘difficulties with written and spoken English’ were often seen (by employers) as ‘problematic’; and it sometimes took time for these workers to ‘adjust to UK ways of working’ (Hussein et al 2008, cited in Moriarty et al 2008, 29).

Our review found some (limited) evidence of responsiveness to the situation of immigrant home care workers. The *Social Care Institute of Excellence* (SCIE) provides a ‘best practice guide’ for employers on its website, which addresses relevant issues, and the agency *Skills for Care*⁴⁶ provides an internet accessible ‘Manager’s Guide’ to the international recruitment of health and social care workers (Hussein 2008). A report prepared by the regional *Tyne and Wear Learning and Skills Council* (2003) also identified the web as an important resource for migrant workers in this field.

The TUC⁴⁷ hosts a website designed to support Polish migrant workers.⁴⁸ Content is in Polish and concerned with helping Polish workers navigate the British employment system, covering health and safety, holiday entitlement and sick pay. Its ‘*Commission on Vulnerable Employment*’ (2007) called for improvements in the treatment of migrant workers coming to the UK, and noted:

Vulnerable workers should have access to advice. This requires more resources for agencies and other bodies working with vulnerable workers. Local authorities should have a statutory duty to fund employment rights advice services.

⁴⁵ This committee of independent economists was set up by the UK Government in 2007.

⁴⁶ *Skills for Care* is an employer-led agency which received substantial public funding.

⁴⁷ The TUC is the Trade Union Congress.

⁴⁸ <http://www.pracawbrytanii.org/>

One of the UK's major trade unions, UNISON (to which many care workers belong), publishes a regular newsletter for migrant workers, which can be downloaded from its website or emailed to anyone who registers to receive it. Membership application forms are available in 17 different languages, all of which can also be downloaded from the website. The website contains regularly updated news items about developments in migrant employment, and resources and guidance on related matters.

Few UK agencies offer tailored ICT-based support for IEM carers, however, as highlighted in a recent report for the Welsh Assembly Government (2003). This study emphasised the need for better arrangements for communicating with this group of carers, and found little evidence of specific support services for them – findings confirmed in other local analysis of the situation of Black and Minority Ethnic carers, including the Carers, Employment and Services study (2006-7) (Yeandle et al 2007).

Several voluntary agencies offering support services to migrant workers in the care work sector were identified during the research for this study:

The Keystone Development Trust runs META - 'Mobile Europeans Taking Action' - a support and information service provided mainly by volunteers and part-time staff. Originally set up in Thetford (England) to support local Portuguese workers, it is now available to a wide range of nationalities. Advice is given on employment-related issues, including the facility to check whether formal qualifications have a British equivalent (drawing on the National Recognition Information Centre's computer programme). META promotes employment rights and arranges appointments for those needing to arrange National Insurance Number interviews with officials. It is currently planning a 'migrant worker to migrant worker' telephone advice service and an action line for employers and practitioners, to be available in five languages, 16 hours a week, with an out-of-hours answer phone, a website and an internet discussion facility.

Kalayaan: Justice for Migrant Workers is a charity offering free, confidential and independent advice on migration and employment. Its website contains useful resources, including signposting for related services, statistics and answers to frequently-asked-questions. There is also a helpline to enable migrant workers to book appointments to receive direct guidance according to their particular needs.

The Afiya Trust, established in 1997, has a web-page for carers,⁴⁹ which identifies the National Black Carers and Carers Workers Network (NBCCWN) as the umbrella network through which the Afiya Trust organises its carer activities. This has already been briefly described as Case Study 8, in Part 3 of this report. Working with Carers UK, with the Association of Directors of Social Services and with the Department of Health, the NBCCWN's regional and London networks represent organisations in both the voluntary and statutory sectors. The NBCCWN holds regional meetings and organises events for Black carers. There are contact details on the web page for the Carer Network Co-ordinator and links to the two publications ('We Care Too' and 'Beyond We Care Too – putting Black Carers in the picture', which can be accessed electronically (as discussed in the previous section of this report).

Part 4 of our report has highlighted the scale and potential need for improved advice, guidance, networks and support for IEM carers and care workers. It nevertheless suggests that, as yet, ICT-based provision for these groups remains relatively under-developed and poorly resourced, despite the opportunity it offers to provide considerably enhanced additional support.

⁴⁹ http://afiyatrust.org.uk/index.php?option=com_content&task=view&id=221&Itemid=53

5. Conclusions and recommendations

5.1 Conclusions

This study has reviewed the potential of ICT in supporting the provision of domiciliary care in the UK. Our report opened with a summary of the English health and social care system as it affects carers and care workers, going on to highlight key data about each of these groups. We drew attention to the widespread nature of unpaid caring responsibilities, most of which are enacted by women and men of working age, and the still strongly feminised nature of the care worker population, which (in the UK) consists mainly of people employed by agencies and organisations, with some ethnic minority groups somewhat over-represented, but without the large numbers of migrant ‘grey labour’ seen in some other European economies.

Our review of recent academic literature, whose findings have also been highlighted in this report, has revealed that, although research in the use of ICT in social care is still in a rather early stage of development, there is already some evidence that technology of this type has significant potential to support carers (alleviating some of the pressures on them and helping them avoid some of the isolation they often face), and that it can be of benefit too to the large numbers of paid care workers who provide care to older, disabled or sick people in their own homes. However, other studies suggest that the new ICT-based developments becoming available are only just beginning to have a significant impact on the way existing health and social care services are provided and that this impact is currently uneven and unsystematic, with opportunities missed and some developments slow to make progress.

One of our main conclusions therefore is that more research is urgently required, to clarify the specific types of situation and the full range of opportunities in which ICT systems of various kinds – ranging from the most sophisticated computer-aided telecare solutions, to comparatively simple (and cheap) developments based on telephone and internet technology – can be introduced, not only to enhance the quality of care offered to older, sick and disabled people (giving them greater independence, choice and dignity), but also to improve the situation of carers and the working lives of care workers. If the full potential of ICT-based solutions is to be achieved, the voices of carers and care workers will need to be heard (alongside those of policymakers and practitioners) in the debates about which developments to invest in and resource. In addition, those providing care in home environments will need more effective and complete information, guidance and extra resources to help them identify what technologies are available and appropriate, and how they can best go about implementing these new developments.

In the UK, a growing number of projects are already in place or in development which can shed light on the opportunities ahead in this field. These examples, some of which we have used as case study examples in this report, highlight some of the important issues which policymakers are likely to encounter in the development of ICT in the field of social care. Already in the past five years, government in the UK has made significant investments (across the country) to explore and showcase the potential of ICT to bring benefits to service users (notably by reducing some of the risks faced by older and disabled people living at home) and to help contain costs in the health and social care system. Our investigations and contacts with key informants make it quite clear that the search is on for robust evidence, based on large and systematic studies, which can answer the key questions which those who manage health and social care budgets and who organise systems of home care support are asking. In these developments and debates, however, a focus on the particular issue under investigation in this small exploratory study – the specific ways in which immigrant and

ethnic minority carers and care workers might benefit from more widespread use of ICT-based systems and support - has been almost entirely absent.

Thus significant initiatives (and some new funding streams) have been put in place in the UK, designed to provide local authorities - which have the primary responsibility for the implementation of social care policy - with the financial capacity and information they need to develop a range of care-based technological interventions (principally through the introduction of the Preventative Technology Grant, designed to pump-prime innovations and investments which can subsequently move into the mainstream of local care and support systems). Alongside (and sometimes in advance of) these developments, other initiatives, schemes and innovations have also emerged, both from local authorities (using other public funds), and from independent or charitable agencies. Opportunities for entrepreneurship and business growth have also been identified among small and medium-sized businesses (including our case study private sector company, Tunstall which acts as the main supplier of telecare equipment, supported by training, to English local authorities and has a sales presence across the UK and in a number of other countries). Many locally and regionally specific ICT services - telephone helplines, websites, discussion forums, radio resources and training courses – have been produced by (or in partnership with) the voluntary and not-for-profit sector. Here our study showed that few organisations were providing services specifically geared towards IEM carers and/or care workers, but found that these were the exception rather than the rule. Only a handful were offering, to migrant or ethnic minority care workers or carers, services tailored to their needs, such as web-based advice and downloadable documents developed with their specific requirements in mind. In the few cases we identified, the emphasis was mainly on supporting these groups with general information and guidance about employment rights and similar matters, rather than with specific advice specifically targeted at those working in the field of social care, or providing unpaid care.

Closer scrutiny of a selection of the projects we identified, in the form of the eight case studies outlined in Part 3 of this report, revealed that ICT was being used in some very interesting and innovative ways across the field of social care. We nevertheless identified a number of schemes and projects developed by different care-based organisations, including charities and non-profit social enterprises, and educational and community organisations. Their recently developed products, some of which had been introduced with considerable success and at relatively modest cost, included internet discussion forms, telephone helplines social networking and blogs, offering help and guidance and a means of communication to unpaid carers, and online training/resources and tools to assist in the professional life and activities of paid care workers.

On the basis of this exploratory review of existing ICT-based developments within the UK's social care system, we can cautiously make a number of recommendations, primarily about the needs for carefully targeted future research in this field.

5.2 Recommendations for research and policy

Our recommendations, which arise from the evidence assembled in our study which has been presented in the earlier sections of the report, address carers, care workers and IEM groups in the context of domiciliary care.

- Future research on the use of ICT in social care needs to involve all stakeholders, including: service users and their (unpaid) carers; the care workers (and their team leaders and managers) who deliver paid support to them at home; healthcare professionals (who could have a potentially much more important role in signposting users and carers to suitable ICT-based support); and the developers and suppliers of the different types of

equipment now becoming more readily available, who are seeking effective ways of getting their socially useful products and services 'to market'. Priorities in this field should not be 'assumed', but need to be based on robust empirical evidence derived from the entire range of relevant stakeholders. The carers and care workers whose (often joint) efforts sustain the whole domiciliary care system must be allowed a significant voice in these new studies, and the least empowered among them, often those with a migration background or belonging to ethnic minority communities, often in areas of socio-economic deprivation, will need to be a specific focus of some of this research.

- We also think there is sufficient evidence already to state that effective awareness campaigns need to be developed without delay to promote the many ICT-based initiatives and solutions already being tested or put in place in the UK. Thus far these initiatives have been provided by 'telecare pioneers', prominent among them a number of resourceful, forward-thinking organisations and agencies (including Tunstall, with its supplier contracts with English local authorities), some care-focused charities keen to exploit advanced technology (e.g. HFT and Carers UK), and certain educational institutions (e.g. City and Guilds). Carers and care workers alike could benefit from a wider range of training tools and accredited courses which would have much to offer, to a larger number (and wider range) of people than presently use them. This will be slow to change, however, unless additional resources are found to enable their development.
- Basic training schemes, highlighting the potential of technology in the social care system, and introducing a wider range of people to the equipment and technology available, would help overcome the lack of knowledge about available options and the benefits of new technology among carers and care workers alike. While many carers and care workers are keen to embrace new technological solutions to the difficulties they face in their increasingly complex caring roles, most currently lack adequate knowledge of existing technologies, or are reticent about taking the first steps in using them. Within organisations, it might be useful to identify a 'technology champion', a person who could look out for new developments, build confidence in using new equipment and services, and pass their knowledge on to other members of staff, service users and carers. Such 'champions' could also play a significant role in ensuring that training in ICT-based care support remains sensitive to the importance of retaining real human interaction and more traditional 'face-to-face' services, and that its role is not to replace, but to supplement and facilitate them, relieving carers and services users of some of the risks, anxieties and pressures which make their everyday lives stressful and difficult.
- Online discussion forums have been shown in this study to be a very successful way of supporting carers in their caring role. These services, which can be put in place at comparatively low cost, establish a 'virtual' community of likeminded others engaging with similar care-based issues and able to offer each other support, and (potentially) sharing solutions to common problems. In developing such forums, agencies need to remain mindful of their responsibilities for monitoring (to restrict abuse by some members), ensuring the privacy/anonymity of users (in some of the examples studied, carers preferred to use pseudonyms), and for signposting users to other available support, drawing on staff and volunteers with suitable expertise using their own experience and knowledge, who have also been provided with suitable training for their role.
- As already indicated, new research on the use of ICT in social care, geared specifically to the situation and circumstances of IEM carers and care workers, is urgently required. These new studies might benefit from engaging directly with organisations keen to investigate the potential of technology for reaching and engaging people with IEM backgrounds, acting as advisers and supporters of their projects. Research on the role of ICT developments in supporting IEM carers and care workers will need to remain

sensitive to different cultural understandings of care-related issues, and to address and overcome any language barriers. In developing this work, researchers will find it interesting to explore differences between and within ethnic minority groups in attitudes, experiences and responses to ICT and telecare options, and to explore whether (when it is thoroughly investigated) the perception that carers in minority ethnic communities are particularly likely to regard ICT-related social care support as of ‘secondary importance’ to more traditional social care services is sustained by evidence.

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Appendices

1. Website details of relevant agencies and organisations

The lists below are not exhaustive, but indicate the range of information available online to inform and support carers.

Local Authority telecare websites

- <http://www.worcstelecare.org/>
- <http://www.careline.org.uk/wow50plus.asp?catid=21262&docid=3459>
- <http://www.eastsussex.gov.uk/socialcare/adults/telecare/default1.htm>
- <http://www.cumbria.gov.uk/adultsocialcare/services/telecare.asp>
- <http://www.mascot-telecare.org.uk/>
- <http://wales.gov.uk/topics/health/socialcare/telecare/?lang=en>
- http://www.ashford.gov.uk/health_and_wellbeing/community_safety/telecare.aspx?theme=textonly
- <http://www.guildford.gov.uk/GuildfordWeb/Community/TelecareServices/National+services/TeleHealthTeleCareServices.htm>
- <http://www.newhampct.nhs.uk/services/telecare/>
- http://www.doncaster.gov.uk/Health_and_Social_Care/caring_for_our_adults/independent_living/Telecare/Telecare_Services.asp
- <http://www.barnet.gov.uk/telecare>
- <http://www2.halton.gov.uk/content/socialcareandhealth/independentliving/helpathome/telecare/?a=5441>
- <http://www.gloucestershire.gov.uk/index.cfm?articleid=13059>
- <http://www.chubbcommunitycare.co.uk/case-studies/telecare-in-hackney/>
- <http://www.gosport.gov.uk/sections/your-council/council-services/housing-services/private-sector-housing/telecare/>
- <http://www.northyorks.gov.uk/index.aspx?articleid=3198>
- <http://www.suffolk.gov.uk/CareAndHealth/Disabilities/HelpToStayAtHome/TelecareandAssistiveTechnologyinSuffolk.htm>
- http://www.herefordshire.gov.uk/health/social_services/32256.asp
- <http://www3.hants.gov.uk/adult-services/telecare>
- http://www.aberdeencity.gov.uk/HousingAdvice/sl_hoa/hoa_telecare_info.asp
- <http://www.greenwich.gov.uk/Greenwich/HealthSocialCare/CommunityCare/CareAtHome/GreenwichTelecare.htm>

Telecare manufacturers, suppliers and information websites

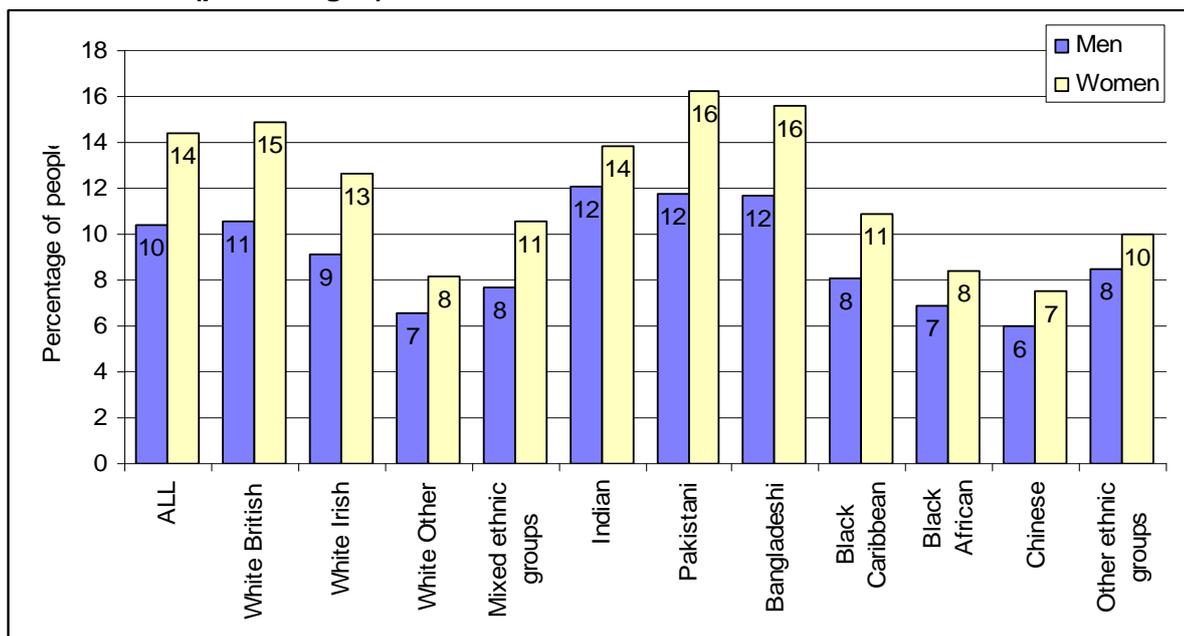
- <http://www.telecare.org.uk/>
- <http://www.telecareaware.com/index.php/what-is-telecare.html>
- <http://www.invictatelecare.co.uk/>
- <http://www.independentliving.co.uk/telecare.html>
- <http://www.livingmadeeasy.org.uk/telecare/>
- <http://www.telecarealliance.co.uk/>
- <http://www.pasa.nhs.uk/PASAWeb/Productsandservices/Telecare/LandingPage.htm>
- <http://networks.csip.org.uk/IndependentLivingChoices/Telecare/?>
- <http://www.hsha.org.uk/telecare/default.asp?ID=29>
- <http://www.ssiacymru.org.uk/index.cfm?articleid=1924>
- <http://www.tkn.port.ac.uk/>
- <http://www.telecaretrainingtool.co.uk/index.asp>
- <http://www.sentinelha.org.uk/telecare.htm>
- <http://www.invictatelecare.co.uk/Default.aspx?sID=765&IID=0>
- <http://networks.csip.org.uk/IndependentLivingChoices/Telecare/AdviceonTelecare/TelecareImplementationGuide/>
- <http://www.foldgroup.co.uk/telecarehousing.php>

Online discussion forums

- <http://www.carersforum.co.uk/forum/index.php>
- <http://www.carers.org/forums/> (Princess Royal Trust)
- <http://www.parents-and-carers.org.uk/cgi-bin/yabb2/YaBB.cgi>
- http://www.frg.org.uk/gpforum/forum.asp?FORUM_ID=3
- <https://www.connectingforcare.co.uk/index.php/forums/member/750/>
- <http://www.carersconnect.com/>
- <http://www.mencap.org.uk/discussion.asp?id=2275>

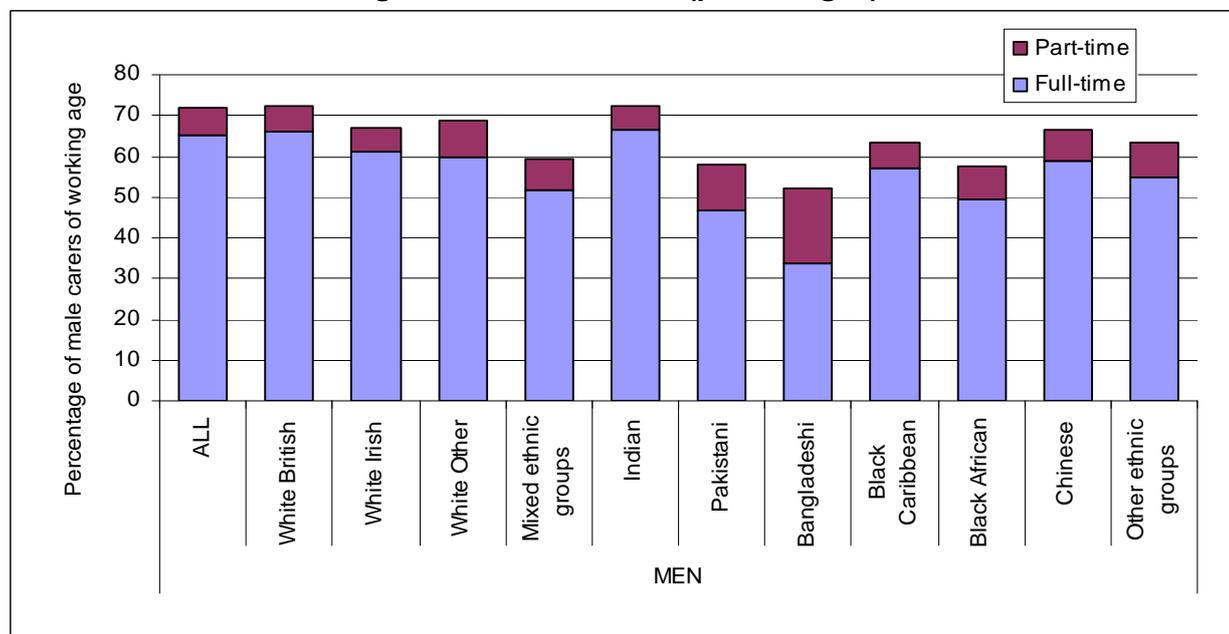
2. Additional data on carers

Figure A1: People of working age who are carers, by ethnic group and sex: Great Britain (percentages)



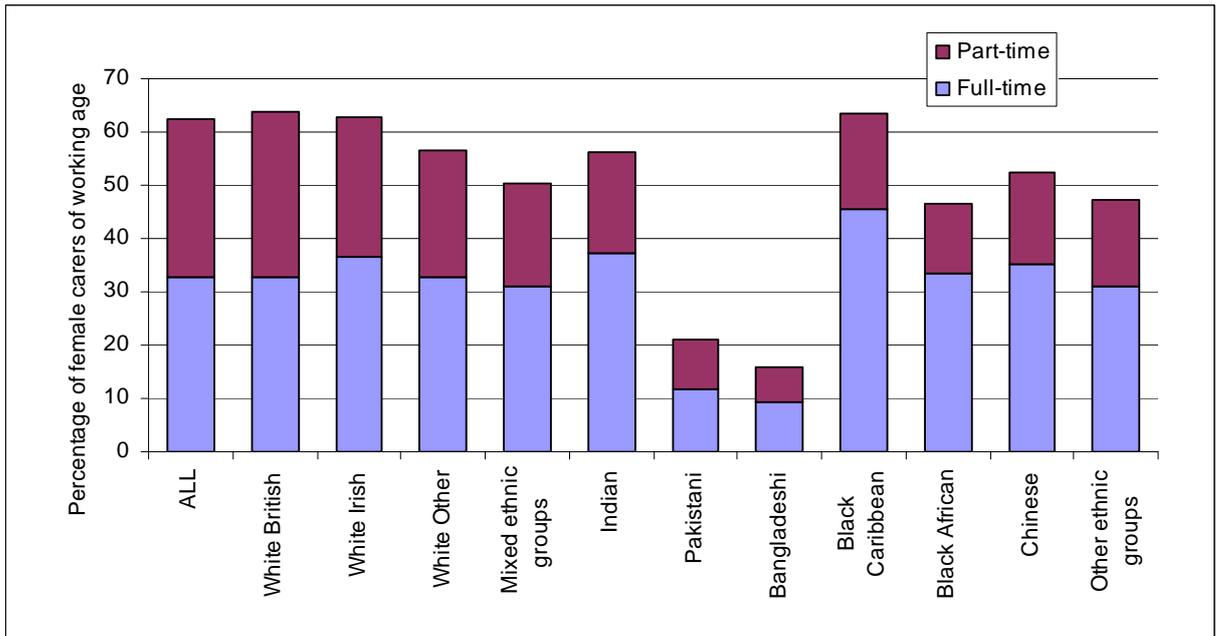
Source: 2001 Census Standard and Commissioned Tables, Crown Copyright 2003.

Figure A2: Men: unpaid carers of working age who are in paid employment, by ethnic group and working hours: Great Britain (percentages)



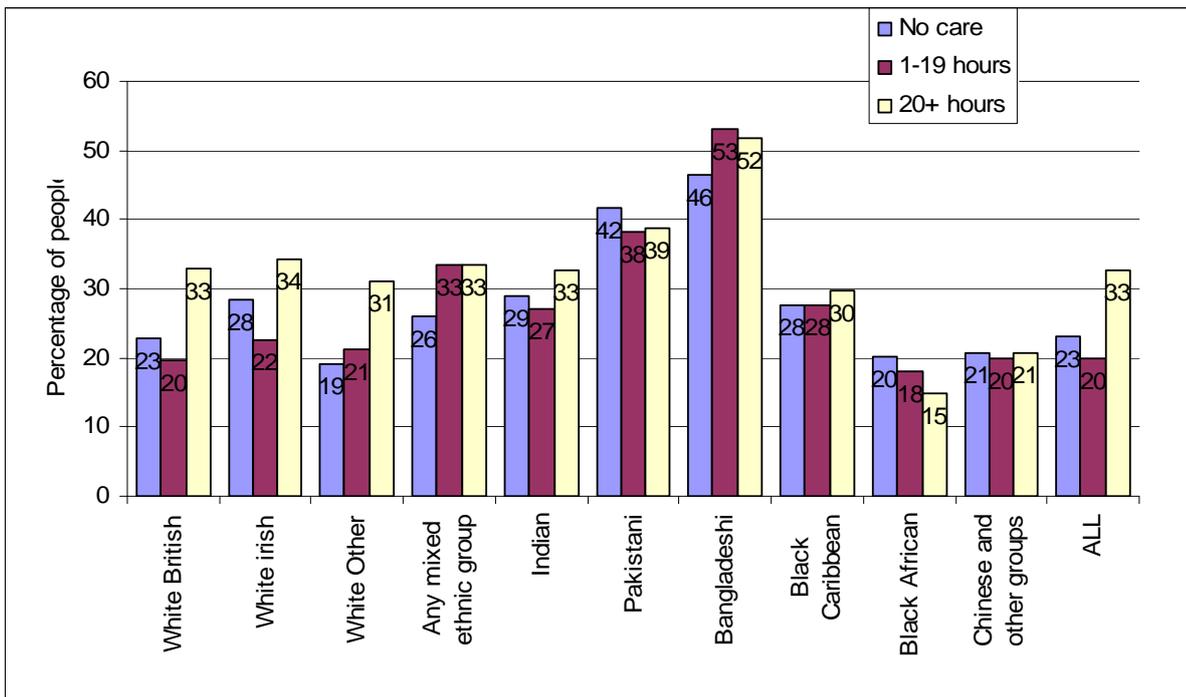
Source: 2001 Census Standard and Commissioned Tables, Crown Copyright 2003.

Figure A3: Women: unpaid carers of working age who are in paid employment, by ethnic group and working hours: Great Britain (percentages)



Source: 2001 Census Standard and Commissioned Tables, Crown Copyright 2003.

Figure A4: Incidence of limiting long-term illness among people aged 45 to state pension age, by ethnicity and caring situation: Great Britain



Source: 2001 Census SARs Crown Copyright 2004. This work is based on the SARs provided through the Centre for Census and Survey Research of the University of Manchester with the support of ESRC and JISC.

Table A1: People of working age: caring by sex, ethnicity and age: selected ethnic groups (percentages)

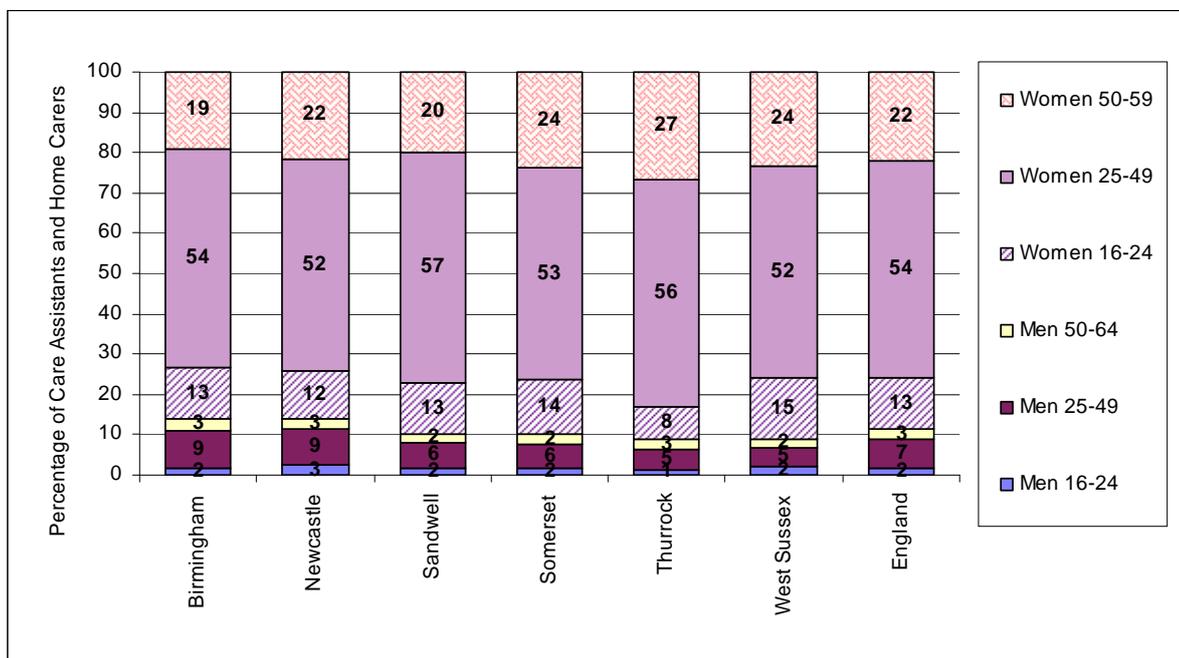
	working age MEN who are carers by age			working age WOMEN who are carers by age		
	16-29	30-64	16-64	16-29	30-59	16-59
All people	4	13	10	6	18	14
White British	4	13	11	6	18	15
White Irish	5	11	9	4	16	13
White Other	3	8	6	4	11	8
Indian	8	15	12	10	16	14
Pakistani	10	13	12	13	19	16
Bangladeshi	10	12	12	13	17	16
Black Caribbean	5	9	8	7	13	11
Black African	5	7	7	5	10	8
Chinese	4	6	6	4	9	7

Source: 2001 Census SARs, Crown Copyright 2004. This work is based on the SARs provided through the Centre for Census and Survey Research of the University of Manchester with the support of ESRC and JISC

3. Additional data on (paid) care workers

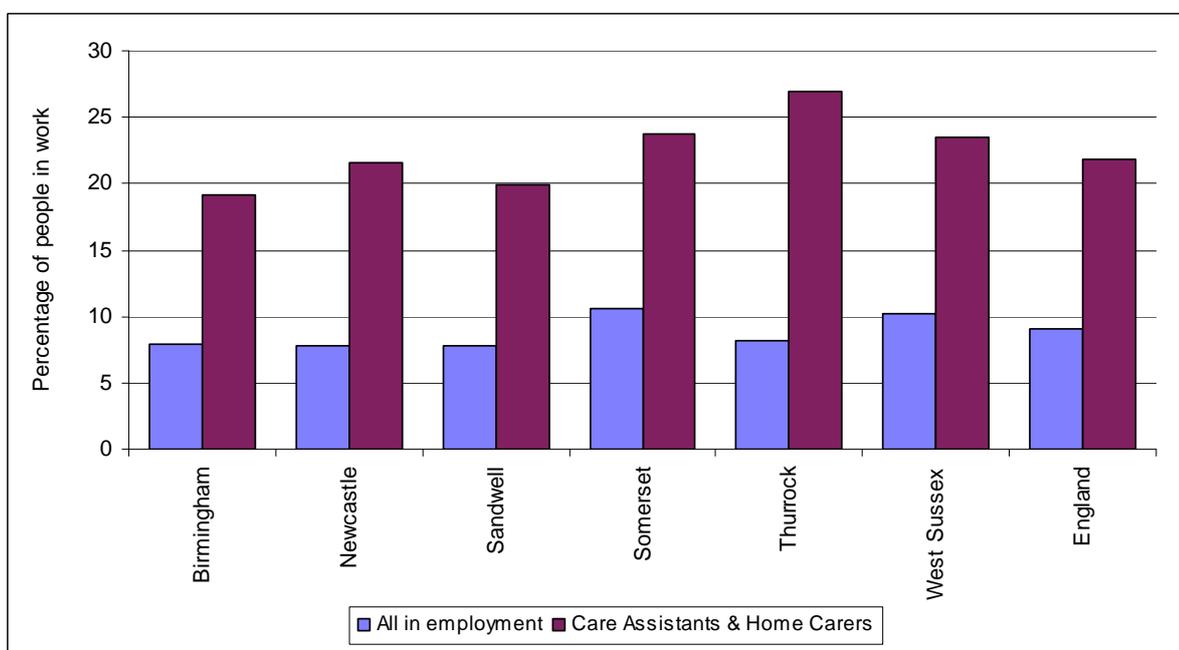
The data in this appendix are drawn from a separate study which explored employment in domiciliary care in six English local authorities. The figures show data for England and for each of these localities, revealing variations and similarities between them.

Figure A5: Care assistants and home carers by age-sex



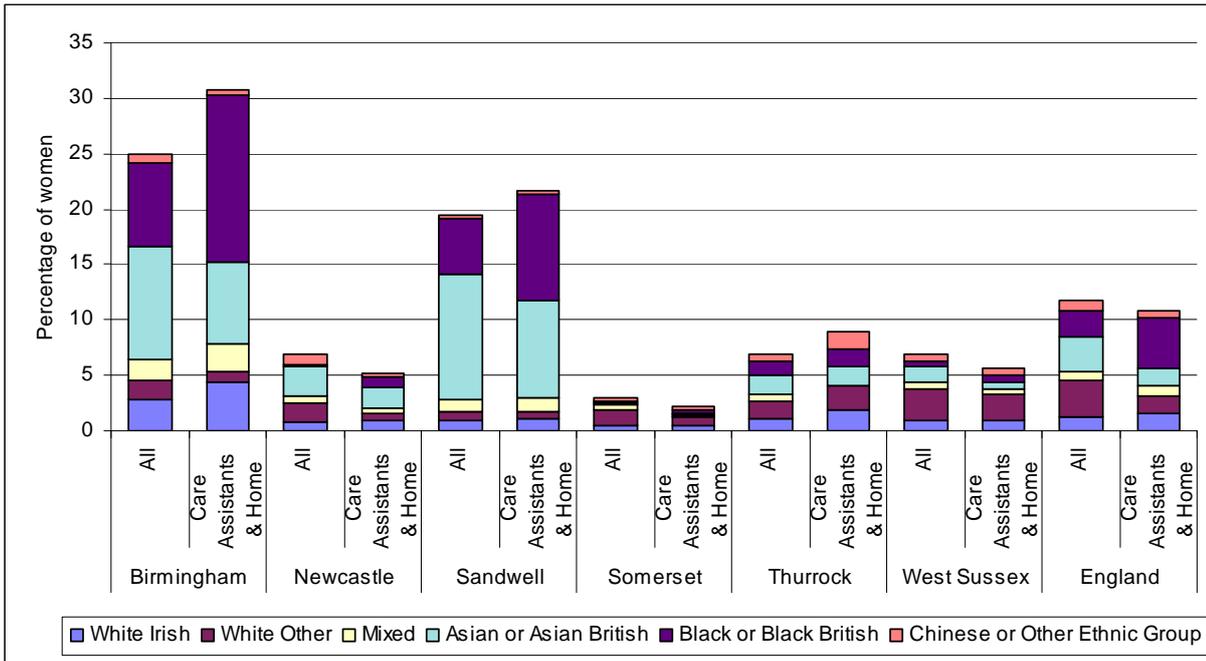
Source: Yeandle et al 2006, 'Local Challenges in Meeting Demand for Domiciliary Care: Synthesis Report' – data derived from 2001 Census Commissioned Tables, Crown Copyright 2003.

Figure A6: Women aged 50-59: total employment / employment as care workers



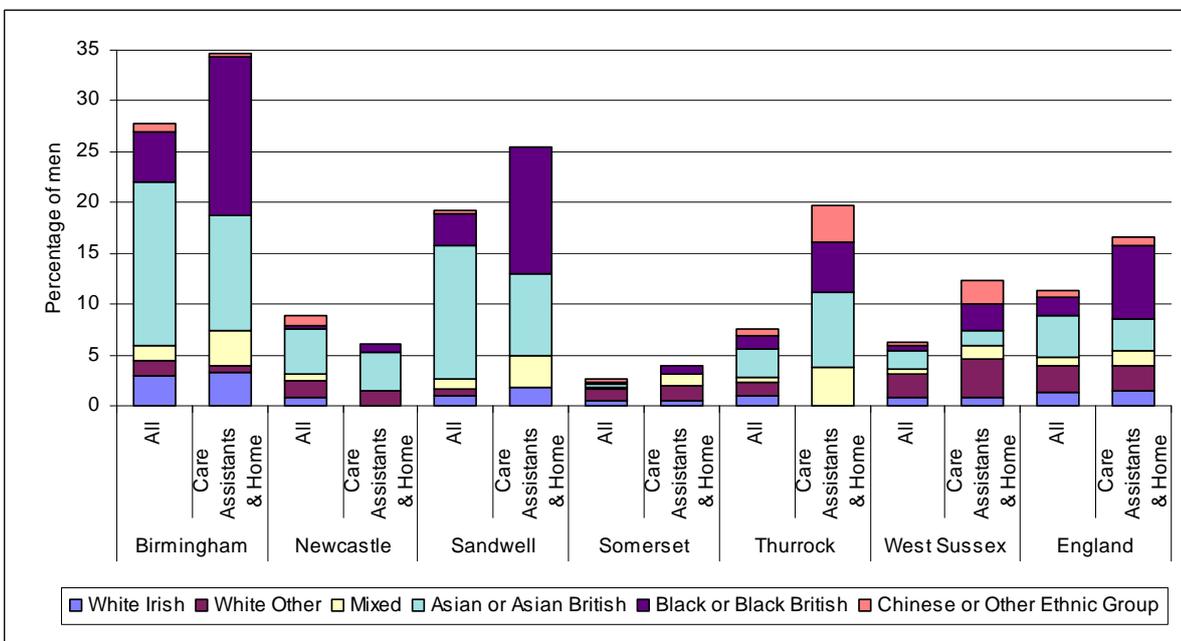
Source: Yeandle et al 2006, 'Local Challenges in Meeting Demand for Domiciliary Care: Synthesis Report' – data derived from 2001 Census Commissioned Tables, Crown Copyright 2003.

Figure A7: Ethnic minority women in employment and employed as care assistants/home carers, women aged 16-59, selected ethnic groups



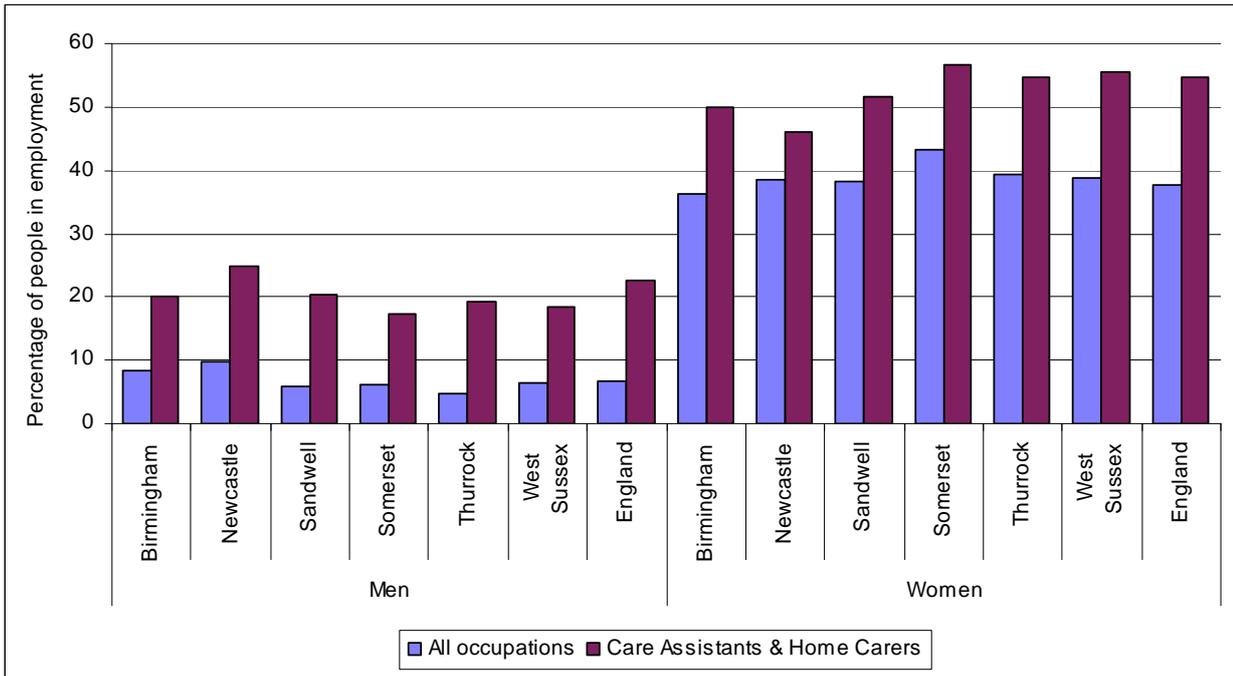
Source: Yeandle et al 2006, 'Local Challenges in Meeting Demand for Domiciliary Care: Synthesis Report' – data derived from 2001 Census Commissioned Tables, Crown Copyright 2003.

Figure A8 Ethnic minority men in employment and employed as care assistants/home carers, men aged 16-64, selected ethnic groups



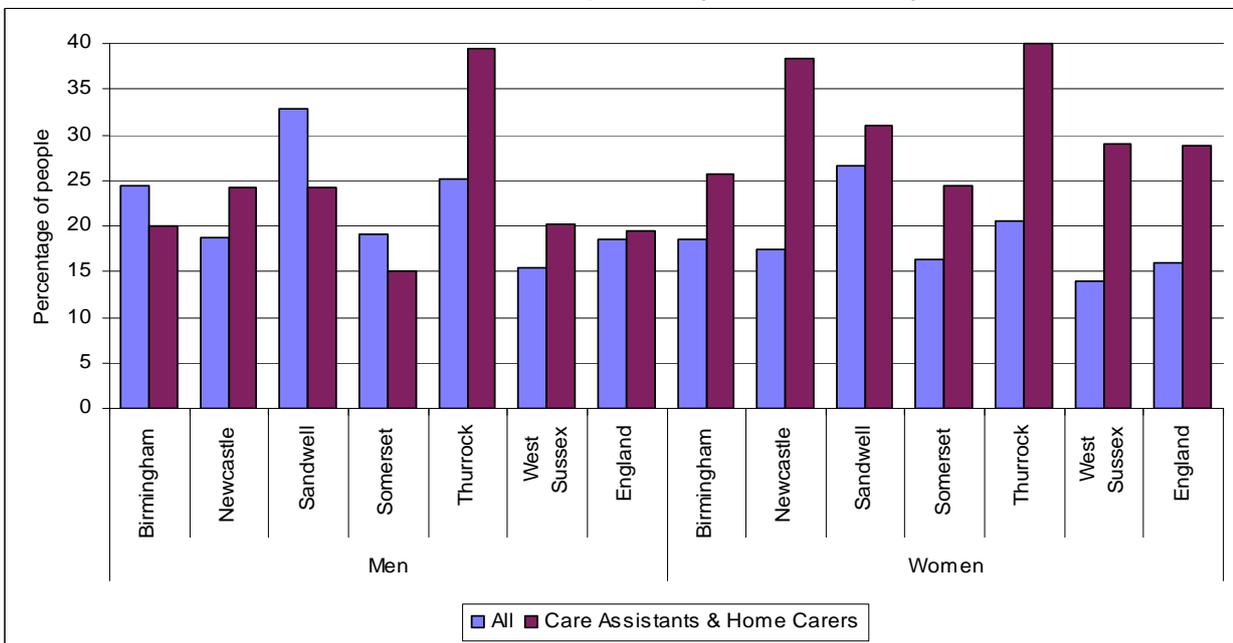
Source: Yeandle et al 2006, 'Local Challenges in Meeting Demand for Domiciliary Care: Synthesis Report' – data derived from 2001 Census Commissioned Tables, Crown Copyright 2003.

Figure A9: Workers employed part-time¹, all employees and care assistants/home carers, by sex and local authority district



Source: Yeandle et al 2006, 'Local Challenges in Meeting Demand for Domiciliary Care: Synthesis Report' – data derived from 2001 Census Commissioned Tables, Crown Copyright 2003.

Figure A10: Men and women in employment who have no qualifications: all workers and care assistants/home carers compared, by local authority district



Source: Yeandle et al 2006, 'Local Challenges in Meeting Demand for Domiciliary Care: Synthesis Report' – data derived from 2001 Census Commissioned Tables, Crown Copyright 2003.

4. Study methods

Literature review

A systematic search of English language literature from 2004 onwards was conducted, to identify relevant academic journal articles relating to ICT and social care. A large body of literature was identified, with the journal articles we considered falling broadly into the following, overlapping categories:

- reports based on findings from pilot studies and trials in which ICT interventions have been trialled;
- policy reviews and debates relating to ICT, telecare and social care;
- proposals for designing social care services which can accommodate new developments in ICT.

For the purposes of the study, we drew on articles from all three of these categories to explore data and debates relating to telecare and telehealth systems, ICT in the form of communication and training, and the policy implications of using ICT to support carers and care workers in domiciliary care situations. Throughout the review we particularly sought articles and reports which considered the situation of ethnic minority and/or immigrant carers and care workers, but found this to be a relatively undeveloped area of investigation during the period of our search.

Case studies

For the case study element of the project, we drew on our existing networks and contacts in the field of social care to gather intelligence and information about possible lines of enquiry. We are very grateful to the study consultant, Madeleine Starr of Carers UK, for her assistance with this task. We also pursued leads identified through our literature and web searches. Agencies and organisations which we thought suitable for this part of the study were then approached by letter or email to make them aware of the study, with this approach followed up with a phone call, during which we made an appointment for a more formal telephone interview wherever possible. The schedule used in these interviews (adapted as appropriate to make it suitable for the agency in question and its focus and activities) is provided overleaf for information.

Key informant interviews

A small number of key informant interviews were also conducted for the study. In setting these up and carrying them out, we used a similar approach to that adopted for the case study interviews, although the focus of the questions was targeted at more specific points of enquiry. A web-search of background information was conducted prior to these interviews to ensure we were well-informed about the general context in advance.

Interview topic guide used in the case study interviews

Introduction

The University of Leeds has been commissioned by the *Institute for Prospective Technological Studies*, to carry out research into the use of ICT initiatives by a selection of organisations in England. [.....] has agreed to participate in this research, and we are now seeking your views on how ICT is used to support social care in your organisation. Any personal information you give me will be treated as confidential and you will not be personally identified in the subsequent report as an individual - or as an organisation, without your explicit agreement to this.

All the questions I will be asking are concerned with the way your organisation is using ICT to support carers and care workers in a domiciliary care setting. We would like to discuss these activities and you approach first with a focus on carers, and then with care workers. We would also like to discuss any ICT-based developments in which you are involved which specifically support of minority ethnic groups.

Do you have any questions about the study before I begin?

Topic 1: Carers

Could you please tell us how your organisation uses ICT activities to support and engage carers in a domiciliary setting?

Prompts if needed:

- Internet forums
- Helplines
- Online training
- Blogs
- Self-help services
- Network facilities

When were these facilities set up? Was this

- A pilot study?
- Mainstreamed?

How much do the facilities cost, and what source of finance do you draw upon?

Prompts if needed:

- PTG
- Carers Grant
- Social care mainstream funding
- Budget plan available?

Do you monitor the use that carers make of the facilities?

Prompts if needed:

- Formal evaluation
- Computer based monitoring
- Feedback process

Which groups of carers have used/benefited from the facilities?

What do you know about the carers who make use of your ICT facilities?

- How many?
- Who?
- Their reactions
- How did they find out about the service?

Do you advertise and promote ICT facilities for carers?

Prompts if needed:

- Online
- Paper literature promotions
- Media advertisement

Do you provide any training for carers in relation to ICT facilities?

Prompts if needed:

- Paper literature
- Formal training courses
- Online support

Do your ICT facilities connect up with other services for carers that your organisation offers?

Prompts if needed:

- Online carers assessments
- Applications for services
- Key contacts

Do ICT activities feature in your forward planning to support carers?

Topic 2: Care workers

Could you please tell us how your organisation uses ICT activities to support and engage care workers in a domiciliary setting?

Prompts if needed:

- Internet forums
- Online training
- Blogs
- Communication with carers
- Supervisory support
- Networking with other professionals

When were these facilities set up (if different from above)?

Prompts if needed:

- Pilot study?
- Mainstreamed?

How much do the facilities cost and what source of finance do you draw upon (if different from above)?

- Preventative Technology Grant (PTG)
- Carers Grant
- Mainstream funding
- Budget plan available?

Do you monitor the use that carers make of the facilities?

Prompts if needed:

- Formal evaluation
- Computer based monitoring
- Feedback process

Are courses/training accredited?

Which groups of carers have used/benefited from the facilities?

What do you know about the care workers who make use of your ICT facilities?

Prompts if needed:

- How many
- Who
- Their reactions
- How did they find out about the service

Do you advertise and promote ICT facilities for care workers?

Prompts if needed:

- Online
- Paper literature promotions
- Media advertisement
- In-house promotion

Do you provide any training for care workers in relation to ICT facilities?

Prompts if needed:

- Paper literature
- Formal training courses
- Online support

Do ICT activities feature in your forward planning to support care workers?

Topic 3: Ethnic minority groups

Could you please tell us if/how your organisation uses ICT activities to support and engage ethnic minority carers and care workers in a domiciliary setting?

Prompts if needed:

- Issues of language
- Advice about cultural integration
- Advice about access to services (carers)
- Advice about access to training (care workers)
- Residential status
- Work permits

When were these facilities set up (if different from above)?

How much do the facilities cost and what source of financial support do you draw upon?

Specific source of funding other than what already mentioned?

Do you monitor the use that ethnic minority groups make of the facilities?

What do you know about the ethnic minority carer and care workers who make use of your ICT facilities?

Do you advertise and promote ICT facilities for ethnic minority carers and care workers?

Do you provide any training for ethnic minority carers and care workers in relation to ICT facilities?

Do ICT activities feature in your forward planning to support ethnic minority carers and care workers?

Request for additional documentary material

Thank you very much for taking part in this interview. In our final report of this study, we hope to draw on a range of information relating to ICT facilities and developments, and we would be very grateful if you could help us with this, by providing any documentation that might help us create a comprehensive case study, based on your organisation.

Alternatively we would like to offer you the opportunity to write a brief description of your ICT-related activities focusing on innovation, effectiveness and good practice.

In the final report we would also like to name your organisation, if appropriate, as a good example of an organisation already using ICT to support domiciliary care, carers or care workers. Some people reading the report may like to get in touch with you to find out more about your work and activities. Would you be willing to do this, and could you provide us with the contact details of a person who would be able to respond to such enquiries?

European Commission

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Authors: **Sue Yeandle and Gary Fry**

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Abstract

The report begins with a brief overview of the social care system in England, providing in particular evidence about unpaid carers (mostly family members, but sometimes friends or neighbours) and the paid home care workers, who support older, sick or disabled people of all ages in their own homes. The variety of ways in which ICT (including telecare) has begun to be used to support those involved in providing domiciliary care is then described, highlighting both major publicly-funded initiatives and investments, and some of the approaches embraced by voluntary and private sector organisations. Eight concise case studies are provided to illustrate more in depth the range of different ways in which these new developments are contributing to the support available to carers and care workers, including through online dialogue and debate among carers. The last part of the report addresses the particular focus on immigrant and ethnic minority carers and care workers, presenting some evidence from the range of available statistical data on this topic (and notes the limitations of the available statistics). Finally, the authors offer some conclusions and cautious recommendations.

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