

The needs of carers in Leicester

Version 9 January 2013

A needs assessment on carers in Leicester

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Executive summary

Carers provide unpaid care by looking after people who are ill or disabled. Often the care recipients would be unable to live independently without assistance. Most carers are adults, but of the 25,000 self-reported carers in Leicester at the time of the 2001 Census, there were 1,200 aged below 18 years. Without appropriate support the personal costs of caring can be high.

Providing support and ameliorating the risks to the health and wellbeing of carers are significant challenges for health and social care services. Evidence indicates that carers have higher levels of stress and anxiety and poorer physical health than the population generally.

This needs assessment shows that in Leicester there are currently an estimated 30,000 carers. While not all need formal support, there is evidence of a large gap between need and service provision. For instance there are 7,000 recipients of adult social care but there are only 1,235 completed carers' assessments. There is inconsistent recording of carers on general practice registers. There are 249 young carers known to social care services, when census results indicate that there may be four to five times as many young carers in the city.

The ethnic background of known carers in Leicester is changing. Based on the proportion of carers' assessments by social care services, carers from Asian/Asian British ethnic backgrounds have increased since 2007/08, from 33.3% to 37.5%. Those from White/White British ethnic backgrounds have decreased from 61.8% to 54.7%.

Carers in Leicester report that they want more recognition and assessment of their needs, commensurate with the caring role. They also require more respite care, more culturally specific services, accessible communication and signposting to helpful services and networks. Services for carers should be flexible; carers need more training and different types of respite care. Not all carers will require or want help, but there is a significant number, estimated to be 16,000 people who could require some degree of support.

The main themes which emerge this need assessment are that service commissioners take steps to:

- identify carers across Leicester by keeping and maintain registers in health and social care
- ensure health and social care providers collaborate to improve the assessment and advice offered to carers; learning from and involving carers at every stage of planning and designing services and changing ways in which services are provided
- ensure that there is consistent formal assessment of individual carer's needs by health and social care staff
- increase the range and provision of respite services for carers
- ensure carers are involved in commissioning decisions
- improve monitoring and data collection from services who support carers.

1. Introduction

A carer provides unpaid care by looking after an ill, frail, or disabled family member, friend or partner. The need to care results from a variety of reasons such as long term illness, disability, mental health problems or old age. Many people will become carers at some point during their lives. The need to care may result from an event or a crisis, or as someone becomes progressively ill. Families provide the majority of care in the UK. Indeed, the contribution of informal carers is worth an estimated £119 billion a year to the UK economy, more than the total cost of the NHS, and more than the combined cost of social care services and private care providers.

Caring can come at great cost to carers. Many give up work in order to care, at the same time they may be faced with considerable additional costs. Young carers are often exposed to inappropriate caring and may not get the support required to enable them to learn and develop. This means that, alongside the strains of ill-health, caring can push people into debt and hardship. Although there is an increased need for care set against limited resources, most carers do not get help.

An important issue for carers is the maintenance of their own health and wellbeing to enable them to fulfil their caring role adequately. A survey of 1,000 carers in contact with carers' organisations found that just under half believed that their own health had been adversely affected by the caring role. There were a range of problems, such as stress (38%), anxiety (27%) and depression (28%). Physical health problems included musculo-skeletal problems (back injury affected 20%) and hypertension (10%)¹.

Other research has found that over a quarter of carers who provide more than 20 hours of care a week suffer from depressive illness, and that carers are more likely to suffer mental ill health if they do not receive periodic respite breaks. The impact of the carers' poor health on care recipients and wider health and social care, is likely to be considerable². The inability of a carer to cope is often the cause of hospitalisation and admission into residential care.

The experience of caring can depend on the circumstances of the care recipient, cultural expectations and wider support from family, friends and local groups. Often support for carers is linked to the care recipient needs, when, in fact, carers may require their own care and support. However, carers are lawfully entitled to an assessment of their needs separate to and independent of the care recipient's needs.

Data from the 2011 Census suggests that there are some 5.4 million carers in England, a rise of 11% from the 4.8 million in 2001³⁴. The 2011 Census suggests that in England there were 3.4 million carers providing 1 to 19 hours of unpaid care per week; 720,000 people caring for between 20 and 49 hours per week 1.2 million caring for more than 50 hours per week. Carers UK research demonstrated that by 2037 there could be a 40% rise in the number of carers.

At the time of the 2011 Census there were a reported 31,000 carers in Leicester responsible for giving at least one hour of care per week. This was a rise of 15% on the 2001 Census figure of 26,868. According to the 2011 Census, in Leicester, there were 17,503 carers providing between 1 and 19 hours of unpaid care per week, 5,533 providing between 20 and 49 hours and 7,929 providing more than 50 hours.

At that time of the 2001 Census carers in Leicester were from different backgrounds. The majority were of working age, although 1 in 6 was an older person⁵. Half of carers lived with the care recipient. There were an additional estimated 1,128 young carers. Two thirds of all carers were female. Within the city, the highest numbers of carers aged 18-64 years were

found in Spinney Hills ward (1,658 carers); the highest numbers of carers aged over 65 years were found in Knighton ward (351 carers). The highest proportions of carers (as a percentage of ward population) were found in Evington and Latimer wards (carers aged 18-64 years) and Eyres Monsell and Knighton wards (carers aged over 65 years). It is likely that this picture will have changed over the last 10 years, and a further update will be provided in a future version of this needs assessment.

The value of the caring role can be seen by the number of people requiring care and the type of problems they face, for instance:

- Carers may look after people at the end of life; there are about 2,500 deaths per year in Leicester. The majority of these deaths are in people over the age of 65 years; the likelihood of dying at home is greatest among the elderly.
- 1,146 people have high support needs related to learning disabilities.
- Many people in receipt of care for a long term condition also have carer support. In Leicester 4,400 people have had a stroke, 10,000 people have heart disease, 3,200 have cancer and 4,400 people have COPD.

National strategy and legislation to protect carers has evolved since the 1990s, with the following key acts and strategies:

Equality Act 2010: This consolidates existing anti-discrimination legislation, including protecting carers against discrimination. It is unlawful to discriminate against, harass or victimise someone who is associated with a disabled person.

Work and Families Act 2006: Gives carers the right to request flexible working from their employer.

The Employment Act 2002: Gives the right to request flexible working to working parents of children under the age of six (or 18 if the child has special needs). From 6 April 2007 the government extended this right, so that it now also applies to employees who care for an adult.

Carers (Equal Opportunities) Act 2004: This act ensures that work, life-long learning and leisure are considered when a carer is assessed. Local authorities have a duty to inform carers of their right to an assessment. This Act gives local authorities powers to enlist the help of housing, health and education in providing support to carers and places a duty on local authorities to inform carers of their right to an assessment.

Carers and Disabled Children Act 2000: This provided a right for the carer⁶ to request an assessment of their needs, even when the disabled care recipient refuses an assessment. It provided a right for parents of children with disabilities to request an assessment, the power for local authorities to provide direct payments⁷ and services which help them to care, vouchers for breaks services.

Carers (Recognition and Services) Act 1995: Gave carers who are providing regular and substantial care the entitlement to request an assessment of their ability to care prior to care planning. Local authorities must take into account the carer's ability to care when looking at what support is needed by the care recipient.

Carers at the heart of 21st-century families and communities 2008:⁸ set out a strategic vision in which carers are recognised and valued as being fundamental to strong families and stable communities. It aimed to meet individual needs and enable carers to maintain a

balance between their caring responsibilities and a life outside caring, whilst enabling the care recipient to be a full and equal citizen.

As for outcomes, the 2008 strategy suggested that carers should

- be respected as expert care partners
- have access to the integrated and personalised services they need to support them in their caring role
- have a life of their own alongside their caring role
- be supported so that they are not forced into financial hardship by their caring role, so that they stay mentally and physically well and treated with dignity.

This strategy also aimed to protect children and young people from inappropriate caring and to support them to learn, develop and thrive and enjoy positive childhoods.

Recognised, valued and supported: next steps for the Carers Strategy 2010,⁹ in which the Coalition Government identified actions necessary to support the best possible outcomes for carers and care recipients, including:

- supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- enabling those with caring responsibilities to fulfil their educational and employment potential
- personalised support both for carers and those they support, enabling them to have a family and community life
- supporting carers to remain mentally and physically well

With regard to financial support the Department of Work and Pensions provides the main support for carers; carers' benefits and employment support. The Carer's Allowance is £58.45 per week for people who earn no more than £100 per week and who provide care for at least 35 hours per week for a person receiving benefits, such as Attendance Allowance, Disability Living Allowance and Constant Attendance Allowance. Carers over the pension age, in receipt of the State Retirement Pension, cannot receive Carer's Allowance. However Carers in this age group who would qualify for Carers Allowance may be entitled to what is known as Underlying Entitlement, which may entitle people to benefits that a retirement pension does not. In Leicester, since 2006 the number of people claiming Carers' Allowance has increased by 34% for people of working age, and by 15% for people of pensionable age.

This needs assessment identifies and investigates the evidence concerning carers in Leicester; looking at level of need, available services, best practice and carers' views. The intention is to encourage feedback about this document so that it can be refined to give better analysis and recommendations and it will be reviewed on a regular basis

At present evidence suggests that the following key issues affect carers in Leicester, which may be alleviated by the recommendations below:

Key issues

This needs assessment suggests that there is,

- inconsistent identification of carers across Leicester
- inconsistent formal social service carers' needs assessment in Leicester
- inconsistent support of carers with mental and physical health problems
- a lack of local knowledge of carers' health needs
- a need for more information regarding young carers' needs
- a need to identify hidden carers within BME communities
- a need to enable carers to understand the services available to them and how to access them
- an increasing number of carers looking after people with complex learning/physical disabilities reaching adulthood
- a need to increase the provision of a range of respite services for carers
- an increase in service use by people who are mutual carers

Recommendations for further discussion:

Commissioners should consider the following recommendations when trying to meet carers' needs:

All carers:

- The development of a joint strategic group to develop implement a Carers' Strategy and Action Plan in Leicester
- An integrated approach across health and social care and the voluntary sector to meet the needs of the increasing numbers of carers
- Flexible appointments for carers accessing health and social care services
- Ensure carers are involved in design and modelling of services which are appropriate to meet the needs of carers before commissioning decisions are made at a local level
- Improve monitoring and data collection from all services who support carers so that needs and trends are better understood
- Provide advice and support for employers seeking to develop carer friendly policy and practice and retain skilled workers
- The development of a health and social care workforce which is trained to meet carers needs and to signpost carers to appropriate local services

Primary Care:

- Identify a lead worker within different General Practices to assist in carer identification and to access to appropriate support
- General Practices should adopt best practice guidance for supporting carers and offer carers flexible appointments and appropriate signposting information.
- General Practices should hold up to date registers of carers and offer carers regular health checks.

Secondary Care:

- Hospitals collaborate with carers and partner agencies to understand the individual needs of care recipients and to reduce the stress experienced by carers which results from hospital admission

- Hospital wards and out-patient clinics should have carers' champions to offer appropriate support to carers
- Hospitals should identify and support new carers, in particular on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics.

Social Care:

- All carers of people in receipt of community based services are entitled to have a carer's assessment.
- A range of carers' services should be developed, with carers, including appropriate and accessible information and signposting, training and personalised services.
- Packages of respite care should be flexible and include in-home sitting services and planned and emergency respite breaks.

2. The level of need in Leicester

At any one time in the UK, 1 person in 10 is a carer¹⁰. The 2001 Census figure for Leicester was 25,473 carers, slightly below the national rate. The amount of time spent caring varies; 20% of carers care for 50 hours per week and more than 30% care for between 20 and 50 hours.

The majority of carers are women although recent national evidence suggests that this gender gap is narrowing as the population ages. Nationally 58% of carers are female. Evidence suggests that women are more likely to care at an earlier age than men¹¹. Women are also more likely to give up work in order to care.

National data suggests that the peak age for caring is 50 to 59 years. More than 20% of people in this age group are providing unpaid care. This compares with 6% of people aged 18 to 34 years, 12.5% aged 35 to 44 and 11.5% aged over 65 years. The number of carers aged over 65 years is increasing more rapidly than the general carer population¹².

According to the 2010 mid-year population estimates, carers comprise 9.5% of the Leicester population; that is approximately 29,000 people. If the proportion of carers to the general population remains the same as in 2012, Table 1 suggests that by 2030 the number of carers in Leicester will exceed 35,000 people. It is important to note that these projections are based on a steady proportion of carers in the population. It is probable that this proportion may change with the ageing population and an increase in long term conditions.

Table 1: Project total number of carers 2012 – 2030 (Based on mid-year population estimates)

	2012	2015	2020	2025	2030
Estimated Population	309,000	322,000	340,000	357,000	372,000
Carers based on 9.5% of population	29355	30590	32300	33915	35340

While not all of these carers will require support, the only evidence that carers' needs are being considered is that 1,233 carers, of 5,046 people receiving community based services, have had carers' assessments. This is not an indication that these carers are receiving support. In addition, there is no systematic evidence of carers who are registered with general practices, although there is an opportunity to register them under the Quality Outcome Framework. More evidence about carers is therefore required to produce a better picture of this unmet need.

Although the greatest increase in carers will be amongst older people, there will be an increase in the number of young carers. There will be higher numbers of carers in communities which currently have a younger demographic profile and those from black and minority ethnic backgrounds. Improved evidence about the numbers of carers requiring support will lead to better understanding of carers' needs and is likely to lead to an increased need and uptake of services.

3. Who do carers care for?

According to a survey by the NHS Information Centre most carers look after their parents or their parents-in-law (40%), with 26% caring for their spouse or partner¹³. 4% care for their grandparents, 7% another relative and 8% of carers look after disabled children. 9% look after a friend or neighbour. Most carers (83%) look after one person, but of the remainder 14% care for 2 people and 3% care for at least 3 people. 58% of carers look after someone with a physical disability; 13% care for someone with mental ill health; 20% for someone with a sensory impairment and 10% for someone with dementia.

Table 2 shows the total clients receiving community based services by client type and age group. It shows that 72% of care recipients in the over 65s have a physical disability; mental illness (12%) and dementia (11%) were the next most frequent client types in this age group. Proportions of client types were more even in the 18-64 age groups. Physical disability was the most frequent client type (36% of clients), with learning disability (34%) and mental ill health (26%) the next most frequent.

Table 2: Number of clients receiving community based services 2011/12

Client type	Age groups			
	18-64		>65	
	Number	%	Number	%
Physical disability, frailty and/or temporary illness	778	36	2075	72
Hearing impairment	8	0	17	1
Visual impairment	27	1	41	1
Dual sensory loss	3	0	2	0
Mental Illness	557	26	348	12
Dementia	10	0	326	11
Learning Disability	739	34	61	2
Substance Misuse	17	1	5	0
Other vulnerable groups	22	1	10	0
Total	2161	100	2885	100

Some evidence of the potential number of carers may be inferred from the wider level of need in the population.

End of life care¹⁴: The proportion of people dying at home increases with increasing age. The majority of these deaths occur following a period of chronic illness, where death may be expected and care is planned. Carers of people who are approaching the end of their lives are likely to be caring for older people with cardiovascular disease, cancer or respiratory disease. In 2010-11 there were 328 people registered on palliative care registers in Leicester.

Long term conditions: Many care recipients have a long term condition. General Practice registers suggest that there are 10,000 patients currently diagnosed with coronary heart disease in Leicester, nearly 4,400 people have had a stroke or transient ischemic attacks, there are 21,138 people registered with diabetes. Nearly 1,250 people in Leicester were diagnosed with cancer in 2009 and there are currently 3,259 patients on a GP cancer register, amounting to 0.9% of the population. In March 2011 there were 18,687 patients recorded on GP registers with asthma in Leicester, and 4,456 patients with Chronic

Obstructive Pulmonary Disease. There are 1,100 people with dementia on practice registers in Leicester.

Learning disabilities: Around 11% of carers in Leicester in 2009/10 said the person they cared for had a learning disability or difficulty. Many carers of people with learning disabilities experience a lifetime of caring for a person in a group which is experiencing increased longevity. Such carers are likely to be caring for 20 hours per week more than those caring for people with other conditions. These carers often negotiate the health, education and social care systems through infancy, childhood and adulthood, becoming experts with many years of experience. For carers of people with learning disabilities, having a break, finding support and getting the best and most appropriate services must be seen in the context of this lifetime of caring. People with learning disabilities have a wide range of needs, including a reduced ability to cope independently¹⁵. Many people with learning disabilities who do not routinely require support often need help in periods of crisis. It is estimated¹⁶ that there are around 5,136 people aged 18-64 in Leicester who have a learning disability; 1,146 of whom have high support needs requiring care service support.

Mental health need: Leicester has significantly worse rates of risk factors for poor mental health and wellbeing, such as high levels of unemployment, lower educational attainment and lower participation in activities that are protective of mental health and wellbeing. Thus the estimated need for carers of people with poor mental health is high and is likely to be long lasting. The number of people in Leicester with serious and enduring mental illnesses, such as schizophrenia, bipolar affective disorder and other psychosis, is about 3,400 people. The estimated number of people with anxiety and depression is about 30,000.

Older people as care recipients: In Leicester 35,600 people are aged over 65 years, of whom 5,200 are over 85: the number of people over 65 is projected to increase to 51,300 by 2030. The majority of older people are female. At present there are relatively fewer people in this age-group from BME communities, but the proportion of older people from BME backgrounds is projected to increase.

Children who provide care: The census results show that Leicester there were 640 children aged 5-15 years who provided care. Of these there were 10 children aged 5-7 years who provided over 50 hours a week. Another 710 young people aged 16-19 also provided care. It is likely that these figures are an underestimate.

Physical and sensory disabilities: Many carers will be caring for someone with a physical or sensory disability, which may reduce the care recipient's movement, sight, hearing, communication and have an impact on their ability to carry out activities of living. The prevalence of physical disability is higher than the number of people who need services. Projecting Adult Needs and Service Information System (PANSI)¹⁷ data suggests that just under 4,000 people aged 18-64 are thought to have a serious physical disability in Leicester. The vast majority of these people live at home. Only 234 are in receipt of social care through self-directed support and/or direct payments.

It is estimated that more than 3,000 people in Leicester are living with sight loss or vision impairment. By 2030 the number of people with sight loss in Leicester is predicted to increase to around to 4,700 people; the most marked increase will be in people aged >65 years.

Traumatic injury: People may become carers as the result of a traumatic event, such as falls or road traffic accidents. Headway suggests states that more than 100,000 people in the UK are coping with the long-term effects of an injury to the brain, equivalent to about 500 people in Leicester¹⁸.

4. Current services compared to need in Leicester

Central government, the local authority, the NHS, the third sector, families and communities all have a role in supporting carers. This section is a review of the services currently available in Leicester.

4.1 Carers Assessments

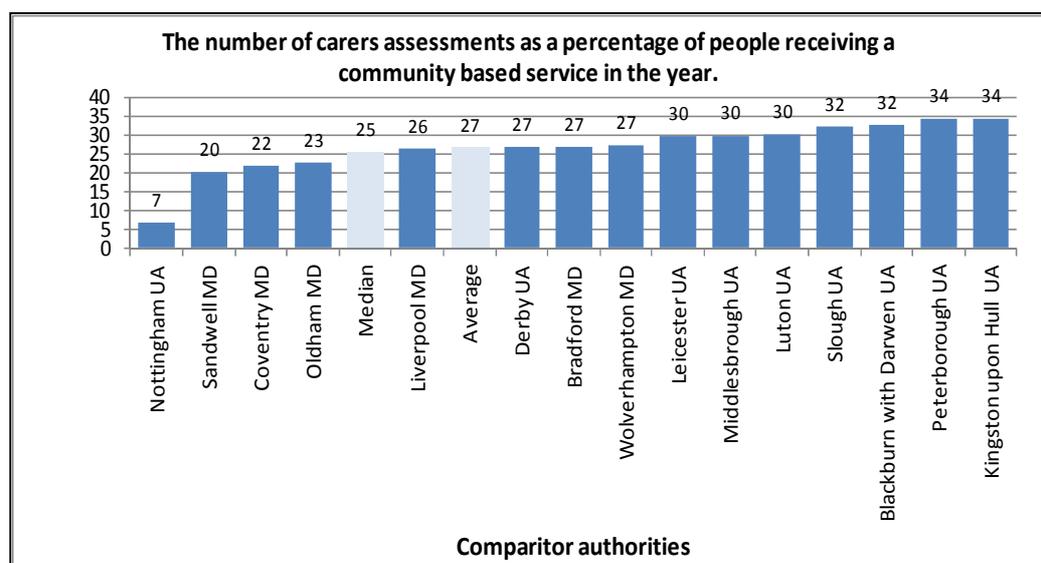
The Adult Social Care (ASC) function of Leicester City Council provides care based on assessment of individual needs. All carers of recipients of social care can be offered a carer's assessment, either separately or jointly with the care recipient. Assessment of carers' needs should enable them to continue their caring role without damaging their own wellbeing.

Social care clients who are eligible for services, and who are not receiving residential support packages, are likely to have carers. Therefore the number of clients in receipt of community care packages can act as a proxy measure for the numbers of people potentially eligible for a social service carers' assessment. In the period 2011-12 there were 5,046 clients¹⁹ receiving ASC packages and 1,233²⁰ carers' assessments and reviews; this equates to approximately 24% of the actual number of carers.

1,152 of these carers received a separate assessment and 81 carers received a joint assessment, with the main care recipient. 220 carers declined an assessment²¹ when offered. Of the carers assessed separately 763 were below 65 years. A further 50 in this age group received a joint assessment. In the over 65s 380 were assessed individually and 13 carers and care recipients were assessed jointly.

Although there is a gap between the number of care recipients and the number of carers' assessments, Figure 1 below²² shows that, in 2010/11, by assessing the needs of 30% of carers of people in receipt of community based services, Leicester was above average for comparator authorities for completed carers' assessments.

Figure 1: The number of carers' assessments as a percentage of people receiving a community based service in the year by comparator local authorities in 2010-11.



4.2 Characteristics of care recipients

Of carers' assessments or reviews completed in 2011-12 for care recipients aged 18-64, the largest proportion (42%) were for people caring for someone with a physical disability; 33% were for people with caring for a person with learning disability and 23% were for carers of people with mental health problems. The proportions were different for older age groups. For those people over 65 years there were a greater proportion of carers for people with physical disabilities (60% of assessments) and mental ill health (39%) and only 0.13% caring for a person with a learning disability.

Carers looking after people in the 18-64 age range with mental health problems were more likely to decline a carer assessment²³. The reasons for declining an assessment are complex. Carers appear to be concerned that if they commit to caring it could reduce the care recipient's allocated resources. However, further feedback from the third sector suggests that there is a feeling that social work resources are focused mainly on assessing care recipients' needs rather than the carers themselves.

4.3 Young carers

The 2001 Census suggested that there were 175,000 young carers in the UK, and 1,128 in Leicester. A survey by the BBC²⁴ estimated that there were more than 700,000 young carers in the UK, which would mean that there could be more than 2,000 young carers in Leicester, Leicestershire and Rutland. This may be indicative of young carers being under-reported. Under-reporting of young carers particularly affects secondary young carers, such as siblings, who may play a significant caring role, often unrecognised by primary carers, such as parents.

Evidence suggests that the average age of young carers is 12 years²⁵. Research shows that young carers are responsible for providing 68% domestic support, 82% of emotional support and 28% intimate personal care. Despite this, only 18% of young carers had a statutory assessment of their needs.

Without a wide range of practical and emotional support young carers are at risk of a range of negative outcomes, such as poor educational attendance and attainment, a lack of time for other activities or engaging with peers, which could affect their life chances. In addition to the risks of social and emotional isolation, young carers experience physical health problems associated with lifting and handling, family stress, identity issues, emotional distress and poverty^{26 27}.

More needs to be done to identify primary and secondary young carers. Additionally, it is necessary to ensure that children and young people are protected from inappropriate caring and that they have the support they need in order to learn, develop and thrive, and to enjoy positive childhoods.

4.4 Ethnicity and caring in Leicester

The 2001 Census showed that there were 503,000 carers from BME backgrounds in England. Caring varies between ethnic groups. People from Bangladesh and Pakistan were 3 times more likely to provide care than people from White/White British ethnic backgrounds²⁸. Carers from different BME backgrounds are often hard to reach, although the evidence suggests that BME carers in Leicester are increasing as a proportion of all known carers in the city.

At the time of the 2011 Census carers from BME backgrounds were more likely to be providing between 20 and 49 hours of care a week. Those BME carers who do care for more than 20 hours a week are less likely to be in employment than those without caring responsibilities. BME carers face difficulties accessing support, are less likely to be consulted about a care recipient's discharge from hospital in-patient care or receive additional primary care support. BME carers are also more likely to miss out on financial support and are more likely to care without practical support from services, family and friends.

The ethnicity of carers in contact with social services in Leicester is changing. In particular the table below²⁹ shows that as a proportion of all carers' assessments conducted by the Local Authority there is a trend towards a greater proportion of people from Asian ethnic backgrounds being assessed and a lower proportion of people from White/White British ethnic backgrounds

Table 3: Carers assessments and ethnicity³⁰ Leicester

Proportion of all carers assessments by ethnicity						
Year	% Ethnic Background					
	Chinese	Mixed	Asian	Black	Unknown	White
2007/08	1.00	0.41	33.27	2.47	1.06	61.78
2008/09	0.95	0.51	34.75	3.80	0.66	59.33
2009/10	0.77	0.51	37.95	3.44	2.17	55.17
2010/11	0.81	0.47	39.76	4.14	2.10	52.71
2011/12	0.55	0.14	37.47	3.34	3.75	54.74
5 year average	0.82	0.41	36.64	3.44	1.95	56.75

4.5 Services provided to carers

The amount and type of care that carers provide varies. Across all carers the frequencies of different care tasks include:

- 82% providing practical help (preparing meals, housework, shopping)
- 38% providing personal care (toileting, bathing, feeding)
- 38% providing physical help (in and out of bed, up and down stairs)
- 35% give medication
- 49% help with financial matters and correspondence.

In Leicester, as a result of receiving a carers' assessment or review, carers over the age of 18 could receive a range of support from respite through to information and advice. According to carers assessment data³¹, in the period 2011-12 there were 705 (57%) carer's services supplied and 528 (43%) cases where information and advice was given. Carers of adults aged over 65 were more likely to be given advice and information.

Services offered to carers may include:

- domestic tasks, such as shopping, cleaning and laundry;
- meal preparation for the care recipient to give the carer a break from cooking;
- once weekly day care, for the care recipient to provide a break from caring responsibilities;

- respite care;
- emotional and practical support and advice;
- equipment;
- direct payments for carers to arrange their own support.

4.6 Respite service packages

Respite and sitting services provide short-term breaks for carers and care recipients in residential care or in a family setting. The need for a break from caring is a consistent theme of carers' responses to consultations³². However accessing respite can be complex; for instance care recipients often struggle to cope without their carer, making it difficult for the carer to take a break for any length of time. Some carers have found it difficult to access respite care because the needs of the care recipient are defined as social rather than health care needs.

Most respite care in 2011-12 was provided to people with learning disability aged 18-64 years and their carers (41% of the total respite provision); people with mental health and physical/sensory issues respectively received 15% and 28% of all respite care in the same period.

For people aged over 65, those with physical and sensory disabilities receive most respite care packages (40%). People with mental health receive 15% and people with frailty and temporary illness receive 17% of all care provided for this age group. Older people with learning disability are less likely to receive services after the age of 65 (3% of respite packages).

4.7 Voluntary sector services

Voluntary sector organisations provide support to carers across the city³³. This support ranges from information, advice and advocacy to training and outreach. For instance, CLASP and Rethink provide carer training. CLASP covers Caring with Confidence, Stress Management, personalisation and first aid. Rethink offer four 12 week Carer Education Training Programmes each year. Other providers offer training around carer awareness, first aid and safeguarding.

Voluntary sector providers also offer support groups and drop-in sessions. Demand for these is great as they give carers a chance to share issues and problems and access valuable peer support.

The models of delivery of support differ between providers. Some work with small groups of carers over a long period of time, whilst others offer ad hoc support. All providers report a high demand for services, which results either in waiting lists or a lack of capacity to take on more service users.

Voluntary sector services for carers face similar pressures to this sector as a whole, indeed they may be exacerbated because carers own personal circumstances are often poor, which in practice means that the operation of support groups is not generally funded. For instance, the funding for the CLASP support group in Leicester was cut in 2003 and the group ceased to function in 2009. Yet it may be argued that the current need for effective support groups is greater than ever, now that eligibility for, and access to, other support is being tightened.

4.8 Services for young carers

In addition to their rights under carers' legislation, young carers may be entitled to services in their own right under the **Children Act**. Leicester's specialist young carers service, **CareFree young carers**, supports young carers living in Leicester and Leicestershire. The service currently supports 248 carers in the city. There are a further 69 children in Leicester whose cases are closed and 168 families receiving a service or who have been referred because of young carers. Over two-thirds of the young carers supported during 2011-12 were female (68%) and over half were from a white ethnic background (54%)³⁴.

The service offers one to one support (e.g. for anger management, building self-esteem and resilience and understanding parental health issues); regular respite groups for time out and peer support; inclusion work to build resilience and engage young carers in their local communities and a range of grant applications (e.g. for holidays, school equipment and clothes, bedroom furniture, IT equipment). There was no evidence available about the care of secondary young carers.

4.9 Parent/carer support to help young people with learning difficulty/disability prepare for Adult Life Transition Planning.

The Leicester City Transition Partnership is made up of a range of partners from Schools, Further Education colleges, Local Authority Disabled Children's Services and Adult Social Care Services, Parent/Carer representative and voluntary sector organisations.

The aim of the Partnership is to work collaboratively to improve transition practice in Leicester. The Partnership produces an annual plan of priorities. Over the past three years, parents and carers of young people with learning difficulties and/or disabilities have been consulted through a number of research projects about what is important to them and what needs to change in relation to transition practice.

The key messages from this local research are that;

- Information needs to be available at an early stage
- Parents/carers need help to signpost them to appropriate support and opportunities whilst the care recipient is aged between 14 and 25 years, so that they are well informed to support their young person to prepare for adulthood.
- Currently the Adult Social Care Transition Team engages in the planning process too late and parents/carers want this to change.

There are a number of developments underway to address parent/carer information needs. These include a new joint funded post between Disabled Children's Service and Adult Social Care Service to specifically address the information needs of young people with Learning Difficulties and/or Disabilities and their parents and carers in the 'Preparing for Adulthood Phase'.

A Family Leadership course is being piloted with two Special Schools. This course consists of 6 modules and is delivered by Leicester City Partners. It aims to help Parents/Carers increase their understanding of Transition Planning Process and the changes that young people and their parents/carers will face as they leave school and Prepare for Adulthood.

5. Evidence for meeting carers' needs

5.1 Impact of caring on carers' health

The caring role may be sustained by a feeling of duty to care; indeed some carers may gain a sense of wellbeing from their role³⁵. However, caring is recognised as potentially stressful for both the carer and the care recipient³⁶, such that carers health and wellbeing is adversely affected by the act of caring. The impact of caring is likely to be exacerbated the longer a person is in the caring role; for some carers this may be many decades. Although carers require support, they are often isolated. Communication with carers can be problematic; carers may have too much or too little information about the care recipient's condition³⁷.

The stress of caring can affect the carer's physical health, especially when the care recipient has limited movement³⁸. 11% of carers report that caring has caused their physical health to get worse³⁹, they also have lower levels of subjective wellbeing and physical health than non-carers⁴⁰. A US study showed 60% of carers reporting fair or poor health status, one or more chronic conditions, or a disability, compared with 33% of non-carers⁴¹. Carers also reported chronic conditions (including heart attack/heart disease, cancer, diabetes and arthritis) at nearly twice the rate of non-carers (45% vs. 24%)⁴².

A survey for Carers' Week 2012 showed that 83% of carers had a negative effect on their physical health, including injuries resulting from manual handling. 87% reported a negative effect on their mental wellbeing (stress and depression)⁴³. The impact of caring is often exacerbated by carers being unable to find time for checks and treatment for their own health. Carers UK found evidence of carers discharging themselves early from hospital because of the absence of alternative care.

Evidence suggests that carers have an increased risk of hypertension and heart disease^{44 45}. Female carers of spouses are more likely to report a personal history of high blood pressure, diabetes and higher levels of cholesterol⁴⁶. Carers also have lower levels of self-care; they are less likely to engage in preventative health behaviours⁴⁷. Carers aged over 65 years have a 63% higher mortality rate than non-carers of the same age⁴⁸.

The 2001 Census found that those caring for more than 50 hours per week are more than twice as likely to be in poor health as non-carers. This was more marked amongst younger age groups. Carers aged 18-25 who provided more than 50 hours of care per week were 3 times as likely to rate their health as not good than non-carers. Many carers described themselves as permanently sick or disabled. Carers in Scotland⁴⁹ found that almost half of carers with health problems reported that their condition started or worsened after they started caring. Rates of mental ill health are higher in those who provide substantial care and those who care for more than 20 hours per week.

Carers attribute the risk to their health as being related to lack of practical and financial support. Where GPs know about carers most said that practices did not do anything differently to accommodate them, and few had a GP who gave carers regular health checks or did home appointments⁵⁰.

5.2 Burden of care

The burden of care is increased when carers are involved with some aspects of personal care, such as managing incontinence. The provision of intimate personal care may be difficult or considered inappropriate for some people, resulting in embarrassment and even

safeguarding concerns. Such issues may create personal difficulties and mean that carers often try to avoid some social situations. Carers may also often find that the burden of care increases in situations where they have to meet certain set appointments in which there is no flexibility of time, or where they have to wait in busy reception areas with a care recipient who may be difficult to manage. Often these issues are carried out against a background in which the carer has had little respite, been frequently disturbed in their sleep by the care recipient, or has experienced a change in their relationship, for instance from a husband or wife to that of a carer⁵¹.

5.3 Social and cultural factors⁵²

Social and cultural beliefs can have an impact on the role of carers, and their readiness to care or accept assistance from care professionals. People holding traditional cultural values may have expectations and obligations to become carers, especially female members of families. In a city as diverse as Leicester, in which the proportion of carers from BME communities is increasing, consideration should be given to understanding the expectations about caring among different communities.

5.4 Services for carers

Engagement of carers at the first episode of illness, or soon after, is beneficial for the long term prospects of those involved in care⁵³. The British Medical Association produced guidance for professionals working with carers. Carers may need extra support at times of transition or where the condition of the care recipient changes. Many carers feel guilt when they are no longer able to cope.

Carers should have both a regular assessment of their needs and a key worker. Cormac and Tihanyi⁵⁴ suggest that an assigned key worker may not always be possible or acceptable, but that a link to the voluntary sector may be more appropriate.

Figure 2: Example care plan for a carer

<p>Information for carer</p> <ul style="list-style-type: none"> • Obtain information on what a carer needs to be able to undertake their care duties • Provide information on how to get help in a crisis • Provide information on how to deal with particular situations • Provide information on where to obtain advice on financial and social matters <p>Plan</p> <ul style="list-style-type: none"> • Define what is required to meet the carer's needs • State how these needs will be met • Record unmet need and attempts to remedy any unmet need <p>Support</p> <ul style="list-style-type: none"> • Provide information on where to get support from carers' groups or other organisations • Plan and obtain respite or short breaks • Provide information about complaints procedures <p>(Source: Cormac and Tihanyi Adapted from Carers Advisory Group, 2001)</p>
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GPs are the first contact for carers, so primary care is well placed to investigate and assess carers' needs. Steps could be taken to protect carers' health by screening for hypertension, depression and other illnesses or by taking health protection measures such as

administering flu vaccinations. Cormac and Tihanyi suggest that primary care staff could give carers relevant information and signpost them to service providers for support. An example of a carers' care plan is given in Figure 2. Part of the rationale for assessing individual carer's needs is to give appropriate advice to carers and care recipients, so that they are able to make informed decisions about care.

5.5 Respite care

Respite care seen is a potentially important way of maintaining the quality of life for carers and care recipients. A systematic review of studies of older carers, including 10 randomized controlled trials, 7 quasi-experimental studies and 5 uncontrolled studies⁵⁵ showed that for all types of respite, the effects upon caregivers were generally small. However, although many studies reported high levels of caregiver satisfaction, there was no reliable evidence to suggest either that respite care delays either entry to residential care or adversely affects frail older people.

A review of respite services and short-term breaks for carers of people with dementia had mixed findings with some policy implications⁵⁶. The benefit of respite to some extent depended on whether the break was aimed at preventing future service use (for instance residential care) or for the immediate relief of the carer⁵⁷. The review looked at a number of models of respite care and feedback from consultations with carers. It found that day care services were of benefit to carers and the person with dementia. Whilst there was some evidence to suggest that day care may prevent entry to long term care, the evidence as to whether day care is cost effective was equivocal; 2 economic evaluations suggested that day care might be cost effective whereas 2 suggested that day care could provide higher benefits only at a higher cost.

Evidence for the effectiveness of respite breaks away from home for one night or more was also equivocal. Organising such breaks was perceived to be difficult. There were some physical and emotional benefits for the carer, with increased sleep for example, but also guilt in using respite services. Some people believed that it helped them to continue in the caring role. For the care recipient, however, there was mixed evidence as to the benefit on their activities of living there was little evidence that overnight respite delayed admission to long term care.

Other models which were considered included in-home and host family respite. Evidence suggests that carers have high levels of satisfaction with in-home respite care and that there was some advantage in maintaining family routines. It was difficult to separate the impact of in-home respite from the demand for other types of respite care or the reduction of the demand for long-term residential care. Carers reported positive outcomes from host-family respite, especially when they wanted to spend time together with the care recipients. It was generally preferred to the alternative of the person receiving care staying in a residential home.

There was some evidence to suggest that support packages which comprise different services may delay permanent admission to long term residential care. However, a minority of studies show that residential respite can worsen service user health. The Social Policy Research Unit (SPRU) found that sometimes there was a contradiction between the value that carers put on respite care and their actual experience of respite; this was also a finding in the Social Services Inspectorate report *Getting the Right Break*⁵⁸. In *A real Break*⁵⁹ there is stress laid upon defining breaks, making it clear who they are for, preparing for the break as well as the quality of the service. The SPRU report emphasised the need for respite care to be based on individual assessment and on-going evaluation. It also suggests that respite

services are most effective when they are underpinned by knowledgeable and supportive doctors, responsive social services, accessible information and supportive care networks.

The University of Leeds produced an evaluation of the Department of Health Demonstrator Sites aimed at improving the health and wellbeing of carers as part of the National Carers' Strategy. These sites looked at the quality and effectiveness of a range of approaches towards breaks for carers, the delivery of annual health checks and ways of supporting carers in NHS settings⁶⁰. The sites showed that strong multi-agency partnerships, including voluntary organisations, are required to identify and engage carers. These links can be developed without disrupting health and social care workloads. However, it was found that some sites needed to adopt special approaches and invest considerable effort in order to encourage GPs to engage with carer support.

Most carers felt they benefitted from the services offered. Flexible and personalised breaks were shown to be of positive benefit for many carers. There was evidence that such breaks had the potential to prevent the deterioration of carers' health and to sustain carers in their caring role. Health checks led to sustained self-care and healthier behaviour for some carers.

The evaluation report also found that carer support can save costs to the health and social care sector. These cost savings included the prevention of hospital or residential care admission, supporting carers to sustain their caring role, earlier identification of physical and mental health problems in carers, efficiency savings in GP practices and assisting carers to undertake paid work.

With regard to policy recommendations, the evaluation and the government consultation on the *Future of Care and Support* were considered by the authors as an opportunity to put some of the findings into practice. These included:

- Involving a diverse range of carers in service development. These carers would be suitably trained and arrangements for their engagement based on flexible local partnerships, involving agencies which are trusted by carers which may be outside the health and social care system.
- A recognition that effective carer support at the local level should always include varied carer support services, which can be adapted to meet individual needs.
- Better support for carers with: health problems and stress; information on how to access suitable support, services, equipment and home adaptations for care recipients; income maintenance and pensions protection during and after caring; self-care, healthy lifestyles and maintaining a life outside of caring; access to education, training, work and leisure; emergency planning; and how to access occasional or regular breaks from their caring role.
- Hospitals should routinely identify and support new carers, centring their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics. Support should be timely and co-ordinated.
- Every GP practice should be encouraged to identify a lead worker for carer support, who can assist in carer identification, help in referring carers to suitable local services, and ensure carers' access to health appointments and treatments is not impeded by their caring circumstances. These workers may require carer awareness and carer support training. The action guide 'Supporting Carers', for GPs and their teams, published by the PRTC and the RCGP in October 2011 provides detailed suggestions for practical ways of taking this forward.
- All staff who interact with carers, in hospitals, GP practices, local authorities and in the voluntary sector should be trained to consider how caring responsibilities can

impact on a carer's health and well-being and be equipped to advise on how a carer can access a health and / or well-being check.

- All relevant organisations should regularly offer carer awareness training to their staff.

5.6 Carers in employment

It is estimated that almost 15% of all employees care for a family member. Given that balancing work with the caring role is stressful it is estimated that 20% of these carers give up work to care full time⁶¹. Given that many carers are aged 45-64 years this means that employers lose experienced staff. With the number of carers in Leicester forecast to increase it is important to encourage employers offer a flexible approach towards the employment of carers in the workforce.

One way of doing this would be to review different forums which offer support and advice to carers in work, in order to influence working practices locally. A group, such as Employers for Carers believes carers should have choices about work. It is a membership forum of large and small employers, chaired by BT and supported by Carers UK. Membership includes British Gas, the Metropolitan Police, the Government Equalities Office, NHS Trusts and local councils. The aim of Employers for carers is to

- Provide advice and support for employers seeking to develop carer friendly policy and practice and retain skilled workers.
- Identify and promote the business benefits of supporting carers in the workplace.
- Influence government and employment policy and practice to create a culture which supports carers in and into work.

The decision for an employer as to whether an individual is a carer is often difficult. However, carers have a statutory right to request flexible working hours if they have worked for an employer for at least 26 weeks, are a parent of a child under 16, or a disabled child under 18, or a carer of an adult dependant who is a relative or lives at the same address.

There are many different forms of flexible working that cover the way working hours are organised during the day, week or year. Flexible working can describe the place of work, such as homeworking, or the kind of contract, or a range of working options such as job-sharing, term time working, annual hours or compressed working hours.

5.7 Overcoming barriers to effective caring

Carers face many barriers to effective caring, For Mansfield⁶² the future focus of work to improve carer experience includes ensuring that 'time off' is adequately covered at the outset in the assessment of carers' needs. It should also include the provision of information about breaks options, direct payments (and the support available to assist with using them) and charging. In addition, there needs to be increased collaboration with service users and carers to increase the acceptability of options to people with care needs.

These ideas are reinforced by the carers' strategy which suggests 4 national priorities:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- Enable those with caring responsibilities to fulfil their educational and employment potential

- Provide personalised support both for carers and those they support, enabling them to have a family and community life
- Support carers to remain mentally and physically well.

6. User views

Feedback from local service users and carers is similar to the evidence presented in section 5. One local survey suggested that carers generally prefer shorter breaks (<24 hours). 34% of carers had used services providing a break from caring for 24 hours or less compared with 26% who had used breaks services lasting more than 24 hours.

Reasons for not accessing services include concerns that the person they were caring for would refuse the service, the cost of services, lack of information about services and the opportunity to choose a holiday rather than a conventional service. The quality of current services did not appear to be an issue. About half of the respondents indicated a willingness to use Direct Payments.

Survey respondents were asked about their knowledge of the services available. Well known services were breaks purchased through the Carers' Personal Budgets scheme (48%) and residential respite organised by the local authority (46%). Respite at home services had a slight lower recognition (38%). The least recognised service was Adult Placement/Shared Care (5%).

When asked about breaks from caring, 52% of respondents had used at least one type of break. The most frequently used breaks were those purchased through Carers' Personal Budgets (28%). 14% of respondents had used residential respite organised by the local authority. Respite breaks attracted high satisfaction rates: 40% of respondent were very satisfied and 46% quite satisfied.

Carers who had not used services were asked to identify significant barriers to accessing services: 22% said that not knowing about the services was an issue, 24% were concerned about cost and 23% said that the care recipient had refused respite (23%).

All respondents were asked whether they would be interested in using direct payments to organise and purchase respite or other breaks: 49% said they would be, although more than a third of these carers said they would require help to use the direct payments. The remaining respondents were either not interested (24%), or did not know (27%).

7. Recommendations for commissioners

Recommendations for further discussion which have been highlighted in this assessment:

Commissioners should consider the following recommendations when trying to meet carers' needs:

All carers:

- The development of a joint strategic group to develop implement a Carers' Strategy and Action Plan in Leicester
- An integrated approach across health and social care and the voluntary sector to meet the needs of the increasing numbers of carers
- Flexible appointments for carers accessing health and social care services
- Ensure carers are involved in design and modelling of services which are appropriate to meet the needs of carers before commissioning decisions are made at a local level
- Improve monitoring and data collection from all services who support carers so that needs and trends are better understood
- Provide advice and support for employers seeking to develop carer friendly policy and practice and retain skilled workers
- The development of a health and social care workforce which is trained to meet carers needs and to signpost carers to appropriate local services

Primary Care:

- Identify a lead worker within different General Practices to assist in carer identification and to access to appropriate support
- General Practices should adopt best practice guidance for supporting carers and offer carers flexible appointments and appropriate signposting information.
- General Practices should hold up to date registers of carers and offer carers regular health checks.

Secondary Care:

- Hospitals collaborate with carers and partner agencies to understand the individual needs of care recipients and to reduce the stress experienced by carers which results from hospital admission
- Hospital wards and out-patient clinics should have carers' champions to offer appropriate support to carers
- Hospitals should identify and support new carers, in particular on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics.

Social Care:

- All carers of people in receipt of community based services are entitled to have a carer's assessment.
- A range of carers' services should be developed, with carers, including appropriate and accessible information and signposting, training and personalised services.
- Packages of respite care should be flexible and include in-home sitting services and planned and emergency respite breaks.

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¹² Carers UK 2011 *ibid*

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¹⁹ RAP form 2011/12 (Return Ref: P1 and P7 Period 01/04/11 to 31/03/12)

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³² (see later par 5. Carer’s views)

³³ See appendix for full breakdown

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