

LEICESTERSHIRE
together

LEICESTERSHIRE JOINT STRATEGIC NEEDS ASSESSMENT



CARERS

SEPTEMBER 2009

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1.1 INTRODUCTION

As a result of advances in technology and medicine, an increasing number of people are surviving with complex health conditions and have multiple needs. They are living longer and have rising aspirations in terms of maintaining maximum independence and control over their own lives against which the demand for care will continue to grow. Consequently, an increasing number of people may find themselves taking on a caring role at some point in their lives. Carers provide unpaid help by looking after or supporting family members, friends, neighbours or others because of long-term physical or mental ill-health, disability or problems related to old age. Providing care can range from helping with shopping, helping to manage finance to providing a substantial amount of care on a regular basis. Furthermore, many carers are juggling work and caring and are frequently providing care from a distance. Many often experience ill health, poverty and discrimination, and struggle to retain a life outside of caring.

The white paper *Our Health, Our Care, Our Say* places continued importance on improving the wellbeing of, and outcomes for, carers of vulnerable adults and children.

In recognition of the changing arena and the challenges associated with the caring role, Leicestershire County Council, in partnership with the local Primary Care Trust, has published plans for the better support of carers over the next three years. The commitments contained in this local plan are in line with the Government's vision for carers as set out in its carers' strategy for 2008–2011, called *Carers at the Heart of the 21st Century, Families and Communities*.

1.2 DEMOGRAPHY

Figures for the total number of carers in the UK have fluctuated between six and seven million since 1985. The most recent figure of six million carers comes from the 2001 Census. However, it is worth noting that the Census from which these figures derive is just a snapshot, as many people do not recognise themselves as carers.

In the UK most carers (5.8 million) are aged over 18 and the peak age for caring is 50 to 59. More than one in five people aged 50-59 (1.5 million across the UK) are providing some unpaid care. One in four women in this age group is providing some care compared with 18% of men. This compares with 6% of adults aged 18-34, 12.5% aged 35 to 44, and 11.5% aged 65 or over.

Over one million of those caring for a friend or relative are caring for more than one person. The age group 35 to 64 currently holds the most carers, however in the future the number of people aged 35 to 64 is predicted to decrease. Caring is increasing alongside the ongoing demand for labour and it is expected that more people will have to combine work with care.

There is also an expected increase in the older population and in the numbers of older people likely to develop dementia. Increased life expectancy for people with some learning disabilities will mean that parent carers are caring longer into old age than previously. By 2017 there will be more people over pensionable age which will further increase the dependency ratio.

1.2.1 Local versus national prevalence

According to the 2001 Census 10% (5,200,000) of people in England and Wales (all ages) are carers, 21.0% of these carers (1,092,000) are providing 50+ hours care per week, 10.9% (572,000) are caring for more than 20 hours per week and 68.1% (3,536,000) are caring for between 1-19 hours per week.

There are 174,995 young people under the age of 18 in England and Wales who provide unpaid care, 13,029 of these provide care for 50 hours or more per week. The vast majority (85%) of all children providing care are caring for 1-19 hours per week.

In Leicestershire there are 63,387 (10.4% of the total population) carers. Of the 63,387 a small number are dependent children (1,568). The majority of carers are female with 33,409 of carers aged 16–74 being female. Of these, 19,722 are in full or part-time employment. A lower number of males are carers, 24,862 (aged 16–74) with 17,475 of these being in full or part-time employment. See Table 1 for further details of the hours spent caring per week.

Table 1: Local versus national carers' statistics

Hours spent caring per week	England		Leicestershire	
	Number of carers	% of total population	Number of carers	% of total population
1 – 19	3,536,000	68.1	47,198	74.4
20 – 49	572,000	10.9	5,718	9.0
50+	1,092,000	21.0	10,471	16.5
All carers	5,200,000	100	63,387	99.9

NB the figures may not total 100.0% due to rounding.

Source: Census 2001

1.2.2 Projected prevalence

Carers UK 2002 report *'It could be you'* demonstrated that by 2037, the number of carers needed in Britain would increase by about 60%, which is equivalent to an extra 3.4 million carers. This is due to demographic change coupled with the direction of community care policy for a more personalised Adult Social Care System. Furthermore, the research showed that every year over 2.3 million adults become carers and over 2.3 million adults stopped being carers and that three in five people will be carers at some point in their lives.

In Leicestershire it is projected that there will be an extra 38,032 people providing unpaid care by 2037. This is due to an increasing number of people wishing to live with dignity within their own family unit, an ageing population and an increasing frail elderly population.

1.2.3 Local carer statistics

The key figures from the 2001 Census show that in Leicestershire there are 63,477 carers in the County of Leicestershire (10.4 % of the total population). Charnwood has the greatest number of people providing care (15,320) followed by Hinckley and Bosworth (10,990 people). For further details see Table 2.

Table 2: Locality specific carer populations

	Number of carers	% of population
Charnwood	15,320	9.9
Hinckley and Bosworth	10,990	10.9
Blaby	9535	10.36
North West Leicestershire	9358	10.9
Harborough	7679	10
Oadby and Wigston	5829	10.4
Melton	4766	9.9

Source: Census 2001

The majority of carers are female with 33,409 of carers aged 16–74 being female. Of these, 19,722 are in full or part-time employment. On average the majority of carers are providing between one and 19 hours care per week. For further details see Table 3 and Table 4.

Table 3: Number of carers by gender and employment status

	Age 16-74	Full or part-time employment
Male	24,862	17,475
Female	33,409	19,722

Source: Census 2001

Table 4: Number of care hours according to locality

	1 to 19 hours	20 to 49 hours	50 or more hours
Blaby	7159	816	1471
Charnwood	11314	1351	2367
Harborough	5990	601	1080
Hinckley and Bosworth	8093	971	1911
Melton	3566	399	809
North West Leicestershire	6454	1065	1827
Oadby and Wigston	4269	495	983

Source: Census 2001

1.2.4 Ethnicity prevalence

In terms of ethnicity, Leicestershire has a low number of carers from Black or Black British and Chinese or Other Ethnic Group than the population of England. See Table 5 for further details. For a breakdown according to district see Table 6.

Table 5: Local ethnicity prevalence (aged 18-64)

	Leicestershire	
	Number of carers	% of total population
White	60,0277	94.7
Mixed Ethnicity	292	0.46
Asian or Asian British	2345	3.7
Black or Black British	196	0.3
Chinese or Other Ethnic Group	336	0.5
Not known	191	0.3

Source: Census 2001

Table 6: Locality specific carer ethnicity prevalence

	White (%)	Mixed ethnicity (%)	Asian or Asian British (%)	Black or Black British (%)	Chinese or Other Ethnic Group (%)
North West Leicestershire	98.7	0.35	0.54	0.09	0.23
Melton	98.7	0.29	0.76	0.08	0.17
Hinckley and Bosworth	97.9	0.37	1.28	0.11	0.30
Harborough	97.8	0.39	1.27	0.15	0.25
Blaby	94.0	0.48	4	0.48	0.49
Charnwood	91.6	0.52	6.4	0.40	1.03
Oadby and Wigston	83.9	0.61	13.7	0.89	0.70

Source: Census 2001

1.3 FACTORS ASSOCIATED WITH CARING

Not all people provide unpaid care equally in society. Many people, mainly women, are balancing work, childcare and caring for an ageing parent. Increasing number of older people often care for their partner while providing childcare for grandchildren, and parents of children with complex health needs know that they will be 'lifetime' carers. Many carers do not have access to sufficient and timely information nor to flexible services to support choice and control over their caring situation. As a result, the impact of the caring responsibility may be higher for some individuals or groups of carers.

The availability of flexible services for cared for people and carers is another factor, for example, service users from Black and Minority Ethnic Communities may not be benefiting from services making the additional impact of the caring responsibility higher for Black and Minority Ethnic Carers.

1.3.1 Health and wellbeing

Cared for people are living longer and healthier lives and the consequence for their carers is that a longer time is spent in the caring role having to cope with complex caring needs. Carers UK national survey in 2008 highlighted the health risks faced by the UK's six million carers with nearly 21% of carers providing more than 50 hours of care per week reporting that they are not in good health compared with only 11% of the non-carer population. The increased health risks are related to both physical and mental health issues.

Figures for the state of the health of carers in Leicestershire show that approximately three quarters (72.3%) are in good health, one-fifth (20.8%) are in fairly good health and the remainder (6.8%) are not in good health. See Table 7 for further details.

Table 7: Health of unpaid carers according to locality

	Frequency (%)			Total
	Good health	Fairly good health	Not good health	
Blaby	58272 (73.3)	16155 (20.3)	5115 (6.4)	79542 (100.0)
Charnwood	94368 (71.9)	27872 (21.2)	9080 (6.9)	131320 (100.0)
Harborough	50827 (75.1)	12901 (19.1)	3923 (5.8)	67651 (100.0)
Hinckley and Bosworth	62923 (71.1)	18955 (21.4)	6593 (7.5)	88471 (100.0)
Melton	31556 (74.0)	8587 (20.1)	2501 (5.9)	42644 (100.0)
North West Leicestershire	52345 (69.3)	16904 (22.4)	6239 (8.3)	75488 (100.0)
Oadby and Wigston	34329 (71.5)	10288 (21.4)	3385 (7.1)	48002 (100.0)

Source: Census 2001

1.3.2 Employment

In Great Britain, 43% of all male carers of working age are in employment, of which 64% are in full time employment. The figures for all female carers of working age are 57% in employment of which 32% are in full time employment. Figures from the 2001 Census show that of the people aged 45-59 who are carers, 28% of these were early retired.

In Leicestershire, of those carers aged between 16 and 74 years, 70.2% of male carers are in full or part-time employment compared with 59.0% of females.

1.3.3 Gender

There are certain groups of people who more frequently provide care. For example, women have a 50:50 chance of providing care by the time they are 50 years old compared with men who have the same chance by the time they are 75 years old.

1.3.4 Ethnicity

Caring varies between ethnic groups. An analysis of the 2001 Census show that caring is almost equal in numbers for men and women across all ethnic groups. However, Bangladeshi and Pakistani men and women are three times more likely to provide care compared with their white British counterparts. In Leicestershire, the largest number of people who identify themselves as carers and access support services are from the white ethnic group. This is reflected in the figures for the numbers of carers from the white ethnic group who received an assessment service (57.3%) from the local authority between April 2008 and February 2009.

1.3.5 Age

Carers span all age groups. The age of the carer and of the cared for person, can have a significant impact on the sustainability of the caring role. The Department of Health estimate that one in four people with learning disabilities are cared for by those aged 70 and over¹. The impact of the caring role on a 75 year old will be different from the impact on a 35 year old in a similar caring situation. Young carers of adults with mental health problems may themselves suffer emotional distress.

1.4 LOCAL AND NATIONAL SERVICE/BENEFIT USE

In Leicestershire there is a wide range of services available to support carers in their caring role. Leicestershire County Council has used approximately 90% of its Carers Grant allocation to support the delivery of services to carers through the local voluntary sector and third sector. An analysis of the take up of all services in April 2007 to March 2008 showed that the greatest was among the white carer population (95.0%) and the lowest was among the Black or Black British and the Chinese or other Ethnic carer groups (4.8%).

Examples of some of the support provided include the provision of emotional and practical support, training and a break from caring. There continues to be high take up of the annual Take a Break Grant to carers and a similar take up for:

- The community carer respite scheme for carers of people with dementia
- The scheme for carers of adults with a mental health
- Carers of people with a learning disability

There is also the recently launched Carer Emergency Response Scheme to offer short-term, home-based cover in the event that the usual carer is unavailable due to an emergency or crisis.

The total amount of the Carers Grant allocated to support Carers Schemes and Carers Services in 2008–2009 is £1,433,530. Table 8 gives the percentage of the budget that is expected to be spent on services to support carers.

Table 8: Carers' Grant 2008-2009 expected spend

People receiving support	Percentage of Budget
Older People	24%
Mental Health	13%
Learning Disabilities (Adults)	15%
Physical Disabilities (Adults)	8%
Young Carers	5%
Other illness	19%

Source: Leicestershire County Council Performance Figures

Over the same period (2006 to 2008) in Leicestershire, approximately 7,000 carers were provided with information and advice and here again, the majority

(82%) were aged over 65 years and caring for service users with a physical disability. See Table 10 for further details.

1.4.1 Carers assessed or reviewed

Database records for 2006 to 2008 show that Leicestershire's Adult Social Care Service provided 13,925 carers with an assessment or a review. The majority (79%) of carers were aged 65+ and caring for service users with a physical disability. Although there has been a small increase in the numbers of carers receiving assessment or review, the trend for these numbers continues to be downward. The majority of completed carers' assessments are completed jointly with the person requiring support.

Table 9: Provision of services and advice to carers

Service User age and user-group	Total Carers reviewed or assessed			Assessed or reviewed Separately			Assessed or reviewed Jointly			Carer declined assessment		
	05/06	06/07	07/08	05/06	06/07	07/08	05/06	06/07	07/08	05/06	06/07	07/08
18-64												
Physical Disability (Total)	644	533	447	34	29	36	610	504	411	0	7	3
Mental Health (Total)	308	95	53	137	5	5	171	90	48	0	0	0
Vulnerable People	445	261	185	31	13	28	414	248	157	0	4	7
Learning Disability	10	2	2	0	0	0	10	2	2	0	0	0
Substance misuse	6	5	2	3	3	0	3	2	2	0	0	0
Total of above	1413	896	689	205	50	69	1208	846	620	0	11	10
65+												
Physical Disability (Total)	3515	2931	2227	99	99	78	3416	2832	2149	2	14	7
Mental Health (Total)	977	676	549	72	45	42	905	631	507	1	3	1
Vulnerable People	19	14	7	0	2	1	19	12	6	0	0	0
Learning Disability	1	3	2	0	0	0	1	3	2	0	0	0
Substance misuse	7	13	7	3	5	0	4	8	7	0	0	0
Total of above	4519	3637	2792	174	151	121	4345	3486	2671	3	17	8

Source: Leicestershire County Council performance figures

1.4.2 Provision of services

Of those carers in receipt of an assessment, 51.8% were provided with services following the assessment and 48.2% were provided with information and advice. See Table 10 for further details.

Table 10: Provision of services and advice to carers

Service User age and user-group	Total Carers getting services or advice and information			Services, including respite for the carer and/or other specific carers' services			Advice and Information only		
	05/06	06/07	07/08	05/06	06/07	07/08	05/06	06/07	07/08
18-64									
Physical Disability (Total)	422	524	447	68	186	194	354	338	253
Mental Health (Total)	196	82	53	194	32	30	2	50	23
Vulnerable People	121	209	185	94	100	113	27	109	72
Learning Disability	6	1	2	1	0	2	5	1	0
Substance misuse	5	5	2	4	2	0	1	3	2
Total of above	750	821	689	361	320	339	389	501	350
65+									
Physical Disability (Total)	2379	2727	2227	655	807	1131	1724	1920	1096
Mental Health (Total)	673	633	549	383	255	310	290	378	239
Vulnerable People	6	11	7	4	6	3	2	5	4
Learning Disability	1	3	2	0	2	0	1	1	2
Substance misuse	4	13	7	0	2	5	4	11	2
Total of above	3063	3387	2792	1042	1072	1449	2021	2315	1343

Source: Leicestershire County Council performance figures

In addition, a large number of carers of people living in Leicestershire have accessed a range of services provided by the voluntary and third sectors. Table 11 and Table 12 below relate to the period 2006/07 and 2007/8.

Table 11: Number of carers in receipt of voluntary sector services

Service Type	Leicestershire 2006/07		Leicestershire 2007/08	
	Number	Percentage	Number	Percentage
Information and Advice	11402	70.3%	13698	74.6%
Break services	573	3.5%	2948	16%
Carers' Services (Carers Act 2000)	2402	14.8%	1259	6.8%
Culturally specific	60	0.3%	80	0.4%

Source: Leicestershire County Council performance figures

1.4.3 Direct payments

In Leicestershire the highest proportion of carers in receipt of direct payments are those caring for the physically disabled. The lowest proportion of carers in receipt of direct payments are those caring for adults with mental health needs. The actual numbers are eight in 2005 to 2006, twelve in 2006 to 2007 and twenty four in 2007 to 2008.

1.4.4 Break services

During the years 2006-2008 carers of people in Leicestershire have been provided with a range of services to support them to have a break from caring. The service with the greatest uptake is the 'Take A Break Grant Scheme' which offers eligible carers a one-off grant of £250 per annum to arrange for support to give them a break. Other high demand schemes are the community respite schemes for:

- Carers of people with dementia
- Adults with mental health needs
- Adults with a learning disability

Figures from the Leicestershire County Council annual Self Assessment Survey (SAS) show that in 2005-06 carers were provided with a total of 10,205 breaks and in 2006-07 carers were provided with 12,662 breaks. Although the take up of these services remain high there are some groups of people that do not access and take up these services. These are:

- Carers of people from Black and Minority Ethnic Communities
- Carers of substance misusing adults
- Carers of people with HIV and AIDS

Table 12: Numbers of carers in receipt of Break service

People receiving support	Numbers	
	2005-06	2006-07
Mental Health needs	226	280
Older people	432	480
Learning Disabled people	239	280
Physically and Sensory Disabled People	508	540
Young carers	5	9
Other people	53	60
Total	1463	1649

Source – Leicestershire County Council Self Assessment Survey (SAS) – services through the Carers Grant

1.4.5 Projections for service use

The projection is that more carers will be seeking to access a range of flexible services to support them in their caring role and to reduce any negative impact from their caring role.

The impact of demographic changes and the drive towards supporting people at home rather than in residential settings will require more non-traditional carer support. In order to care for those with complex health needs carers will need to be better informed and trained and will require support to maintain their own health and wellbeing.

Carers will be expecting to have greater recognition of their role and to be more involved in development of Support Plans for the service user.

The Leicestershire County Council and Leicestershire County and Rutland NHS joint Carers Strategy 2008–2011 has given a commitment to extending the range and accessibility of break opportunities for carers with a particular focus on access at times of crisis or emergency.

Carers will be encouraged to have more control over their assessment and the support they receive. Work has begun on processes to support carers self assessments and self identification of support solutions which will improve the potential for delivering better outcomes for carers of people in Leicestershire.

See Table 13 for details of service use projections.

Table 13: Projections for service use (Carers receiving services)

	2009-2010	2010-2011
Number of carers' assessments – joint assessments with the service user or separate carers' assessments	3,692	3,722
Number of carers receiving break services	3,000	3,850
Number of carers receiving an Individual budget (including Direct payments)	60	65
Number of carers receiving Carers' services	800	850
Number of carers receiving information and advice	3,150	3,800

Source: Leicestershire County Council Performance Figures

1.5 CARERS' PERSPECTIVES

A range of consultation exercises have been undertaken with carers in order to ascertain their views on the support they receive and their aspirations for future support.

1.5.1 Breaks from caring

In 2006 a survey of carers of adults with learning disabilities in Leicestershire found that the majority of carers identified the need for a break from caring as highly desirable. Many were already accessing break/respice support of the traditional type (e.g. day care and health respice) but the majority expressed a wish to access an individual budget to plan and secure their own break/respice solutions.

A similar survey in 2006 of carers of older people showed a similar response. However, most carers wanted better break services for the person they were supporting including longer opening hours at day centres. A small number of carers expressed a wish to take their break with, or in the company of the person they were supporting (this was specific to husband and wife couples). This group was less in favour of accessing a direct payment to organise their own break support.

1.5.2 Carer Involvement

Carers' representatives have been and continue to be involved in the development of services through a variety of formats. For example, carers are represented on many reference groups in Adult Social Care. These include the:

- Leicestershire Learning Disabilities Partnership Board
- Adult Mental Carers Action Group

- Valuing People Carers Sub-group
- Aspergers Planning Group
- Children and Young People Partnership Group
- Older Persons Engagement Network

All Carers Projects hosted in the voluntary sector and in receipt of financial support from the Leicestershire County Council Adult Social Care Service have, as a contractual requirement, to involve carers in service development and service reviews.

As part of the consultation on the Leicestershire County Council Carers' Strategy 2008-11, carers have expressed a willingness to participate in the implementation of this Strategy and the delivery of the related Action Plan. A Multi Agency Carers Strategy group has now been established and carers are represented in the group.

There is a need to plan for greater and wider involvement of carers in, for example, the delivery of training and more consistently with statutory sector in their work around service design and service procurement.

1.5.3 Employees who are carers

In 2005 a Leicestershire County Council survey of employees identified that greater effort is required to promote the need to, and the benefits of, supporting employees to manage their caring role. The results highlighted the need for better and wider awareness-raising among staff and managers. Additional messages from carers who responded was the need for:

- More, flexible respite
- Better access to information especially at the beginning of their caring role
- More one-to-one care for the cared for person
- Longer opening hours at day care
- Help around the home
- Training for carers in relation to the appropriate management of physical and mental health conditions
- Training for carers in relation to looking after their own health.

Consequently, Leicestershire County Council has prepared a Charter for Employees who are carers which is published on the Leicestershire County Council website.

1.6 KEY MESSAGES

The role of carers will be more important to supporting people within their own homes. More people will be living longer, including people with complex health needs due to advances in technology and the medical field. Some carers will need more and different type of support as there is an expected increase in

the numbers of people living in the community with long-term life limiting health conditions.

In Leicestershire, there is already a wide range of support for carers. However, the people accessing this support are predominantly from the White population. There are very few culturally specific services to support carers from Black and Minority Ethnic communities in their caring role and where these exist, they are not well used.

There will be a need to enable more people to identify themselves as carers, to assess the impact of their caring role on their lives and, to access and utilise the range of available support services.

Many carers seek support directly from the voluntary sector and have a desire to continue to do so and to see more development in this area. They are particularly interested in early intervention and preventative services.

The provision and availability of information about carers' rights and the availability of carers support needs to be improved. This was one of the messages from the 2007 National Consultation for the new ten-year National Carers Strategy.

There is a need for more robust data gathering about the make up of the local carer population. Statistics about the age, employment status, ethnicity and gender of all carers would give a clear picture of need and use of support.

The Government is expecting local partners, in particular Local Authorities and Health to give a commitment to identifying and supporting carers. There is Government funding available to both sectors to help develop this support, in particular the availability of breaks for carers. The joint Leicestershire County Council/Primary Care Trust Carers Strategy 2008-11 will be the main vehicle for enabling delivery on this commitment.

Local carers have been involved with key partners in the identification of support needs and in the construction of possible support solutions. These carers are willing to continue to give this support.

1.7 FUTURE SERVICE AREAS

1.7.1 Personalisation and self directed support

Carers and those who are cared for should have increased choice and control. In order to achieve this, the Adult Social Care Service need to ensure that carers are included in the transformation of social care services in line with the personalisation agenda. Practically, this will include involving carers in the support planning for the person requiring support. Furthermore, carers will need to be supported to identify the impact of caring on their own health and wellbeing and supported to make choices about whether and how they wish to undertake the caring role.

1.7.2 Joint planning and commissioning with the local Primary Care Trust

In line with the commitments contained within the National and local Carers Strategy there will be a need for a greater emphasis on this area of service planning. Staff within Community Health Services and GP surgeries will need to be proactive in identifying carers, their need for support in their caring role and for enabling carers to maintain good health and wellbeing. Most carers will have support needs that require a mixed response. For example, carers of people with limiting long term illness will need advice and support for the giving of personal care and at the same time a break from caring.

Through partnership work with the Primary Care Trust, Leicestershire County Council will continue to develop processes to support carer identification, carers' assessments and support to carers following assessment. This is a key target within the local Joint Carers Strategy and in the Local Area Agreement 2 National Indicator (NI) 135 commitment.

1.7.3 Involvement with other local partners

It is acknowledged that there is a need for carers to become 'everybody's' business and that their need for support is acknowledged across all related authorities. Many carers wish to (and do) receive early intervention and preventative services, most of which are provided by organisations other than the local authority. It is essential that particular attention is given to these already established partnerships and to the need for the development of new and/or different partnerships.

1.8 REFERENCES

¹ Valuing People. A New Strategy for Learning Disability for the 21st Century" Dept of Health. 2001.