Carers

JSNA Insight Pack

July 2020
From 2019 the Northamptonshire JSNA will consist of a collection of three types of presentation, an Insight Pack, a JSNA Briefing Document and an In-Depth Needs Assessment. Definitions of these products are below. In addition other work that compliments the JSNA, or is of interest or is similar to the three types of product mentioned will be published alongside the JSNA products if it is appropriate and helpful to do so.

This is a JSNA Insight Pack focused on Carers.

**Insight Pack**
An Insight Pack will highlight the key facts and local needs about a particular subject. This will be presented, where possible, in a very visual format with charts and infographics and will include relevant data produced with comparisons.

There will be a short narrative accompanying this which will provide an overview of the subject. This may result in recommendations for further, more detailed work in the JSNA programme.

**JSNA Briefing Document**
A JSNA Briefing Document is designed to provide an overview of a subject area, usually accompanied by an Insight Pack (though not all Insight Packs will be accompanied by a Briefing Document).

The Briefing Document will summarise the local needs, risk factors, current services in place, evidence to support commissioners and considerations and recommendations for local commissioning. This product may result in recommendations for more detailed analysis and/or an in-depth Needs Assessment.

**In-Depth Needs Assessment**
An In-Depth Needs Assessment will include a detailed analysis of the subject area. Typically this can take up to 6 months to deliver and will usually only be completed if it is either clear at the outset that one is required or a JSNA Briefing Document has been completed that recommended an In-Depth Needs Assessment be delivered.

Each full needs assessment will be delivered by a working group and truly delivered in partnership across all relevant organisations for the subject area.
Introduction

What is a carer?

Carers look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid. This includes adults looking after other adults, parent carers looking after disabled children and young carers under 18 years of age looking after siblings, parents or other relatives.

A carer is not a volunteer who has been placed in a caring role by a voluntary organisation, nor someone who is paid as a care worker or personal assistant.

A young carer is a child or young person under 18 who provides care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances. The term young carer does not apply to everyday or occasional help that may occur in all families. It is specific to care that is relied upon in maintaining the health, safety or day to day wellbeing of the person receiving support or care.

The Care Act 2014

The Care Act helps to improve people’s independence and wellbeing. It makes clear that local authorities must provide or arrange services that help prevent people developing needs for care and support or delay people deteriorating such that they would need ongoing care and support.

The Care Act relates mostly to adult carers – people over 18 who are caring for another adult. This is because young carers (aged under 18) and adults who care for disabled children can be assessed and supported under children's law.

The Care Act does not deal with assessment of people under the age of 18 who care for others. The Children and Families Act gives young carers (and parent carers) similar rights to assessment as other carers have under the Care Act.

69% of women and 58% of men in England will become carers at some point in their lives.

Half of these female carers will have been a carer at age 47. The age that half of the male carers will begin to be a carer is 60.

The Children and Families Act

Section 96 requires local authorities to assess whether young carers within their area have support needs and, if so, what those needs are. The right to an assessment of need for support extends to all young carers under the age of 18, regardless of who they care for, what type of care they provide and how often they provide it. Local authorities must take reasonable steps to identify the extent to which there are young carers within their area who have needs for support.

Section 97 requires local authorities to assess whether parent carers within their area have support needs and, if so, what those needs are. The local authority should take reasonable steps to identify the extent to which there are parent carers within their area who have support needs. The requirement that carers provide a substantial amount of care on a regular basis in order to be assessed is removed.
Introduction

Unpaid carers save the UK economy £19bn each year.

Research by the University of Sheffield placed the value of unpaid care in Northamptonshire in 2015 at £1,333,000,000.

Research by Manchester Metropolitan University highlighted that for every £1 invested in young carer services, the saving to the Exchequer and wider society is £6.72 (Crossroads Caring for Carers and The Princess Royal Trust for Carers, 2008).

An evaluation of Sheffield Young Carers Service identified for every £1 invested into the schemes, between £1.42 and £1.90 of benefits is estimated to be generated (Ecorys, 2016).

NEF consulting was commissioned to conduct a cost benefit analysis of UK wide programme Young Adult Carers Services: Time for Change. The programme was delivered by local young carer services and focused on key areas including education, employment and mental health. Some of the findings included the net state value created per young carer which was found to be £86.21, therefore for every £1 spent, £1.77 is saved by the state (NEF Consulting, 2016).


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Overview

There are an estimated **75,350** unpaid carers in Northamptonshire.

Approximately **2,000** of these are aged 15 or younger, around **19,400** are aged 65 and over.

These estimates have been produced by applying the proportion of carers in the county’s population at the last census in **2011** and applying it to the latest population estimate from the Office of National Statistics which at the time of writing was **Mid 2019**.

In **2011**, **10%** of Northamptonshire’s population provided unpaid care to family, friends or neighbours. This is the most recent estimate of proportions of carers available.

Northampton is the borough with the lowest proportion of carers with **9.3%** of the town’s residents providing unpaid care but as the most populated borough is home to the largest volume at around **20,900** people, **28%** of the county’s carer population. The highest proportion is found in Daventry District at **10.9%**.

53% of Northamptonshire’s carer population will reside in the new West Northamptonshire unitary area. Using 2019 population estimates that’s estimated to be almost **40,000** people, around **35,500** in North Northamptonshire.

Three in five people are carers at some point in their lives.

You can find out more about the numbers of identified carers in the 2011 Census, including their age ranges and the numbers of hours of care they provide at the [NOMIS website](#). The data is presented by borough/district.
Overview

12,860 – Adult carers registered with Northamptonshire Carers, September 2019

1,766 - Number of new adult carers registering with Northamptonshire Carers between October 2018 and September 2019

1,016 – Young carers registered with Northamptonshire Carers, September 2019 (166 cases reviewed to close after 2 years non engagement)
Young carers

We estimate there to be at least 1,600 carers aged 15 and under in Northamptonshire.

This estimate is obtained by applying the proportion of young carers at the time of the 2011 census to the ONS 2019 Mid Year Population Estimates.

The traditional definition of a young carer is a person under 18 who provides or intends to provide care to another person. However due to the way the 2011 Census data is presented by NOMIS, the estimates used in this document are for young carers aged 15 and younger.

Charities and organisations working with young carers have long thought the census figures to be an underestimate. Research carried out by BBC News and Nottingham University in 2018 presents a very different picture. 22% of the children completing the questionnaire provided some care for a family member with an illness or disability. Of that 22%, 32% were doing what the study called a high level of caring and 9% were doing what the study considered the highest level of caring. The questionnaire was completed by 925 children across England from two year groups - 11 to 12-year-olds and 14 to 15-year-olds.

If the survey was extrapolated across England it would correspond to more than 800,000 secondary-school age children carrying out some level of care. Of those, the survey suggests more than 250,000 young carers are carrying out a high level of care, with 73,000 taking on the highest amount of care.

YouGov conducted a survey on behalf of Barnados in December 2017 of young carers aged 7 to 24 receiving their support. This survey found;

- Two thirds of the young carers stated that they began caring whilst they were still in primary school and 1 in 8 had started caring at the age of 5.
- Most young carers are caring for their mother.
- Over 50% of young carers are giving emotional support, shopping, attending medical appointments and completing household chores as part of their caring role.
- Over half of young carers are looking after someone with mental or physical disabilities and a third for someone with a long term illness or disease. 10% are caring for someone with a drug and/or alcohol misuse problem.
- The average age of a young carer in the UK is 12, with some children as young as four caring for members of their family.
- A quarter of young carers surveyed completed more than 30 hours of care per week. 27% were unable to estimate how many hours they give.
- Nine out of ten teachers surveyed were concerned that some young carers remained ‘unidentified and unsupported’.
- Over 90% of our young carer practitioners surveyed said that they believed there were young people who did not want to be identified.
Older carers

We estimate there to be around 19,400 carers aged 65 and over in Northamptonshire, 141 out of every 1,000 people in this age group.

Unsurprisingly, the highest number of carers live in Northampton, the borough with the largest population.

When viewed as a rate, Kettering and Daventry have the highest proportion of older people providing unpaid care. The new North Northamptonshire unitary area will have a higher proportion of older unpaid carers than the West, although 52% of the county’s carers will live in the West Northamptonshire unitary area.

Numbers of older people providing unpaid care are predicted to increase between now and 2035, an additional 7,700 people are expected to become older carers in the 15 years between 2020 and 2035.

The rate of unpaid older carers per 1,000 population is predicted to decrease over the next 15 years, but please note the number of older carers is increasing. The number of older people is increasing at a faster rate meaning there are potentially more older people requiring formal care or have unmet need.

52% of the county’s older carers are expected to live in the West Northamptonshire unitary in 2035, same as now. The figure to the left shows the predicted rate until the same year.
Unpaid care in Northamptonshire

The Personal Social Services Survey of Adult Carers in England (SACE) is a biennial survey that took place for the first time in 2012-13. The survey covers informal, unpaid carers aged 18 or over, caring for a person aged 18 or over. A summary of the results can be found on the following pages, the full survey results can be found here.

The first figure to the right shows the types of care provided by unpaid carers in Northamptonshire. The most common activities are practical assistance such as dealing with paperwork, finances and benefits, emotional support, keeping them company and taking them out and in almost 92% of cases just keeping an eye on the person they care for.

Over a third of carers in Northamptonshire are giving more than 100 hours of care a week. 56% are giving more hours than could be considered a full time job (35 hours or more). A quarter of all carers are over 65.

Over 85% of carers in Northamptonshire are either retired or not in paid work.

More than half of Northamptonshire’s unpaid carers have been providing care for more than 5 years, almost a third have been doing so for 10 years or more.
Unpaid care in Northamptonshire

Almost 75% of unpaid carers are looking after someone over the age of 65. Almost a quarter are caring for someone aged 85 or over, a proportion close to that of those caring for people aged 18 to 64 (25.7%)

Half of the people receiving unpaid care in Northamptonshire have a physical disability. 41.6% have a long standing illness and almost 40% are suffering from dementia. A third need care due to the ageing process

62% of carers are also experiencing a health condition or illness. 31% have a long standing illness of their own and 22.4% have a physical disability or impairment. Nearly 20% have a sensory impairment.

77% of carers in Northamptonshire live with the person they care (2018-19)
Carers support in Northamptonshire

The Personal Social Services Survey of Adult Carers in England (SACE) contains several questions relating to services available to both the carer and the person being cared for.

The figures on this page show the responses to a selection of these questions, the full response can be found at the link on the previous page.

45% of Northamptonshire carers responding to the Personal Social Services Survey of Adult Carers in England survey in 2018-19 received no support or services from Social Services.

69% of carers receiving support from Social Services in 2018-19 were satisfied with that support. 16% were dissatisfied.

The majority of carers were not utilising support to allow them to take a break from their caring roles.

**Question 4** - Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?

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<th>Support Received</th>
<th>Extremely Satisfied</th>
<th>Very Satisfied</th>
<th>Quite Satisfied</th>
<th>Neither Satisfied Not Dissatisfied</th>
<th>Quite Dissatisfied</th>
<th>Very Dissatisfied</th>
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**Question 5a** - Has the person you care for used any of the support or services listed, in the last 12 months? - Support or services allowing you to take a break from caring at short notice or in an emergency

- Yes: 11.8%
- No: 86.9%
- Don’t know: 1.3%

**Question 5b** - Has the person you care for used any of the support or services listed, in the last 12 months? - Support or services allowing you to take a break from caring for more than 24 hours

- Yes: 12.6%
- No: 85.7%
- Don’t know: 1.3%

**Question 5c** - Has the person you care for used any of the support or services listed, in the last 12 months? - Support or services to allow you to have a rest from caring for between 1 and 24 hours (e.g. sitting service)

- Yes: 16.1%
- No: 83.0%
- Don’t know: 0.9%
Carers support in Northamptonshire

Almost two thirds of respondents had asked for information and/or advice and half had sought support from carers groups or someone else to talk to in confidence.

The majority of respondents had not accessed training for their caring role or support to maintain their employment. Most respondents were not in paid employment, nearly 17% as a result of their caring role, 63% for other reasons including retirement. 4.2% of respondents felt that they were not supported in their caring role by their employers and 1.6% were self employed but found they couldn’t balance working and caring.
Almost half of carers in Northamptonshire feel they are not taking adequate care of their own needs and almost two thirds would like to have more social contact.

Over two thirds of carers reported feeling tired, disturbed sleep and general feelings of stress. Half said they felt depressed, and short tempered and irritable. Around one in three had caused themselves some form of physical injury through caring.

21% had developed a health condition of their own which they attribute to their caring role and 25% have visited their own GP as a result of caring for someone.

The following page shows the responses to some of the financial questions in the SACE.

44% of carers have experienced financial difficulties as a result of caring, 11% say it’s had a big impact.

A quarter of respondents did not try to find information or advice about financial support services or benefits, but of those who did over half (58%) found it easy to do. Most of them found the advice or information they received to be helpful.

Of those who have been involved in discussions about the support or services provided to the person for which they care, 36% felt they were always involved or consulted, 34% felt they were usually involved or consulted. Almost 8% felt they were never involved or consulted in such discussions.
Support for carers in Northamptonshire

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**Question 15 - In the last 12 months, has caring caused you any financial difficulties?**

- 55.9% No, not at all
- 32.9% Yes, to some extent
- 11.2% Yes, a lot

**Question 16 - In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits?**

- 25.0% Very easy to find
- 8.6% Fairly easy to find
- 33.7% Fairly difficult to find
- 20.2% Very difficult to find

**Question 17 - In the last 12 months, how helpful has the information and advice you have received been?**

- 39.5% Very helpful
- 26.3% Quite helpful
- 20.4% 6.3% Quite unhelpful
- 1.5% Very unhelpful

**Question 18 - In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?**

- 37.5% I have always been involved or consulted
- 22.7% I usually been involved or consulted
- 20.9% I sometimes been involved or consulted
- 14.4% I never been involved or consulted
- 4.7% 8.6% There have been no discussions that I have been aware of, in the last 12 months

**Question 16 - Excluding those who answered "I have not tried to find information or advice in the last 12 months"**

- 32.8% Very easy to find
- 44.9% Fairly easy to find
- 25.4% Fairly difficult to find
- 18.7% Very difficult to find

**Question 18 - In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?**

- 35.8% I always felt involved or consulted
- 35.5% I usually felt involved or consulted
- 20.1% I sometimes felt involved or consulted
- 7.6% I never felt involved or consulted
Carers Allowance

Those who provide care for someone else for at least 35 hours a week may be entitled to Carers Allowance, which amounts to £66.15 per week at the time of writing.

In May 2018, there were 12,122 claims entitled to receive carers allowance, with 8,052 claimants in receipt of benefits payments at that time.

In 2016, before the DWP changed the way their data was recorded and published, the number of claimants in Northamptonshire receiving the benefit was 6,270.

Carers allowance payments can be suspended for a number of reasons, for example if the person receiving care has been in hospital or a care home for at least 28 days, the benefits received by the person receiving care change or the amount of care given falls below 35 hours per week.

The first chart, below left, shows the numbers of carers allowance claimant who are eligible (this includes suspended payments) and the number who are in receipt of carers allowance in May 2018.

The second shows the age of claimants in 4 age bands, under 25, 25 to 44, 45 to 64 and 65 and over.

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Coronavirus and the impact on caring

In July 2020, the Office for National Statistics released a bulletin looking at the impact of the coronavirus pandemic of 2020 on the provision of unpaid care in the UK. In the first month of the national ‘lockdown’, April 2020. The lockdown saw a dramatic increase in the numbers of people providing unpaid support to someone, a third of those found to be providing voluntary support were doing so for someone new.

The findings are summarised below, the full bulletin can be found here.

48% of UK adults report providing help or support to someone outside of their household during April 2020. Pre-pandemic the proportion of adults providing some regular service or help for an elderly, disabled or ill person living outside their household was 11%.

Of adults who reported providing help in April 2020, 32% were helping someone who they did not help before the pandemic and 33% reported giving more help to people they helped previously.

Shopping was the most common activity that people undertook as part of their caring responsibilities (85%), followed by providing or cooking meals (19%).

People aged 45 to 54 years were most likely to report caring, with 60% of this age group reporting that they had provided help or support to someone during the first month of lockdown. The age group most likely to report caring in 2017 to 2018 was 55-to-64-year-olds (20%).

Although women are still more likely than men to be taking on these caring roles, with 51% undertaking these activities, there was also a high proportion of men providing help and support to someone outside their household through April, 45% reporting doing so.

There has been the largest change in reported levels of poor mental health between women who were providing support in 2017 to 2018 and women who were providing support in April 2020.

Between 3 April and 10 May 2020, 79% of adults said they were very or somewhat worried about the effect that coronavirus was having on their life and 11% of these said their caring responsibilities had been affected by the pandemic. Almost half (47%) who said their caring responsibilities had been affected said they were unable to care for someone they usually supported. Nearly 15% also said they had to organise remote support for someone vulnerable and 9% said that paid support had reduced.

For carers and non-carers who said they were very or somewhat worried about the effect that coronavirus (COVID-19) was having on their life, the most common reasons were feeling worried about the future, feeling stressed or anxious or being bored. However, carers were more likely to say there was a strain on their personal relationships, their mental health was worse, or they did not have anyone to talk to about their worries.
Risk factors

**Young carers**
- Children and young people with parents or siblings who have a mental illness or suffer drug and/or alcohol misuse
- Children and young people with parents or siblings who have a physical or sensory disability
- Children and young people caring for someone who needs medication
- Children and young people caring for someone with life threatening and life limiting conditions
- Children and young people who are heavily involved in caring
- Children under 8 with caring responsibilities
- Children and young people in military families
- Children of prisoners/ex-prisoners with a disability, mental health or substance misuse
- Special Educational Needs and Disabilities (SEND)
- Black and minority ethnic (BME) groups
- Families in poverty
- Children and young people in single parent homes
- Not in Education, Employment or Training

**Adult carers**

The impact of caring can be detrimental to carers’ health owing to a number of factors, including stress related illness or physical injury.

Carers UK’s ‘In Poor Health’, found carers who provide high levels of care for sick, or disabled relatives and friends, unpaid, are more than twice as likely to suffer from poor health compared to people without caring responsibilities. Analysis of the Census shows that nearly 21% of carers providing over 50 hours of care say they are in poor health compared to nearly 11% of the non-carer Population.

Carers UK’s analysis of the 2001 Census findings, found that those caring for 50 hours per week or more are twice as likely to be in poor health as those not caring (21% compared with 11%).

Carers may experience financial hardship as a result of their caring role. The Carers UK State of Caring 2016 survey (17) showed that 44% of those surveyed ‘are struggling to make ends meet rising to nearly half (48%) of those caring for 35 hours or more per week. A quarter of carers (26%) report that they have been, or are currently, in debt as a result of their caring role.’