

**Solihull Carers  
Needs Assessment**

**August 2017**

**Solihull Observatory**

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## Executive Summary

In 2008 the Government defined a carer as someone who “*spends a significant proportion of their life providing unpaid support to family or friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.*”

Every year over 2.1 million adults become carers and almost as many people find that their caring responsibilities come to an end. This ‘turnover’ means that 3 in 5 people will be carers at some point in their lives.

Families provide the majority of care in the UK, outstripping social care services and private care providers combined. The contribution of the country’s 6.5 million carers is worth an estimated £132 billion, nearly as much as the total annual cost of health spending in the UK.

The value of carers is recognised in a range of Government policy and legislation from the National Carers Strategy and subsequent Action Plan through to the Care Act (2014) and the Children and Families Act (2014).

The Care Act 2014 recognises carers in law in the same way as those they care for. Carers who are over 18 will be entitled to an assessment of their support needs. There will be a shift to self-directed support and flexibility in fitting services around the family. The act has a key underpinning principle of the prevention of the escalation of need and there is an increased emphasis on integration.

The Children and Families Act 2014 states that local authorities in England must assess whether a young carer within their area has needs for support and, if so, what those needs are.

### Solihull Carers

At the time of the 2011 Census around 24,100 Solihull residents identified themselves as being a carer, representing nearly 12% of the total population. The Solihull total includes:

- 5,100 individuals providing 50 hours or more care per week (21%), with a disproportionate number of these living in Solihull’s more deprived neighbourhoods;
- 5,900 aged 65 and over (25%), who are more likely to undertake more intensive care and have health needs themselves;
- 400 under the age of 16 years (1.2% of the population aged 5-15 years);
- 1,400 who say that their own health is either bad or very bad (6%) and;
- 13,100 who combine caring with paid employment (8,400 full-time, 4,700 part-time).

Applying results from the NHS Survey of Carers in Households to the Solihull carer population it can be estimated that the Solihull total includes:

- 4,100 providing care for two or more people (17%);
- 8,900 who are the sole carer for the cared for person (37%);
- 12,100 caring for someone aged 75 and over (50%);
- 1,900 caring for someone under the age of 16 (8%);
- 9,100 who provide physical help and similar number providing personal care (38%);

- 14,000 who care for someone with a physical disability, 2,400 for someone with dementia, 3,100 for someone with a mental health problem, 2,650 for someone with a Learning Disability and nearly 1,000 for someone with a terminal illness.

Future demographic trends suggest that the number of self identified Solihull carers will increase to 27,000 by 2020 and over 31,000 by 2030. Increasing numbers of older residents with care needs and dementia will be the key driver, with a smaller impact attributable to adults with a Learning Disability living longer. Our local projections are broadly consistent with a national one developed by Carers UK. However, analysis by Age UK questions whether a range of factors including changing family structures, greater geographical dispersal and an over-reliance on older carers will limit the capacity of families to meet this additional demand.

<b>Projected Increase in Solihull Carers</b>			
Year	Solihull Carers	Increase Compared with 2011	
		Number	%
2011	24,100		
2017	25,600	1,500	5%
2020	27,000	2,900	11%
2025	29,600	5,500	22%
2030	31,400	7,300	29%
2035	33,100	9,000	36%
<i>Sources: ONS/Solihull Observatory</i>			

A range of other local data shows that:

- 22% of Solihull patients aged 18+ responding to the GP practice survey indicated that have a caring responsibility, compared to 18% nationally. This equates to over 42,000 patients aged 18+. At a practice level the proportion ranges from 9% to 25% of registered patients.
- There are over 2,400 carers actively engaged with the Solihull Carers' Centre of which 545 are under the age of 25 and classified as a young carer;
  - Among those aged 25 and over a relatively high proportion care for someone with a Learning Disability, with those caring for a person with a physical or sensory disability or frail elderly under-represented compared to national survey evidence.
  - 74% of registered young carers are under the age of 16 (178 aged 5-10, 226 aged 11-15);
  - Compared with the Census a large proportion of registered young carers live in the three North Regeneration wards (57% compared to 35%).
- In May 2016 there were 2,480 Solihull residents in receipt of a Carers Allowance (1,930 female, 550 male). Estimates suggest that around 1,300 Solihull carers may be eligible for, but not claiming Carers Allowance.
- Evidence from the 2016/17 Carers Survey suggest that carers in contact with Solihull social services are for more likely to have intensive caring responsibilities than the wider carer population;

- 39% say that they provide 100+ hours of care per week, 69% provide personal care, 54% give physical help.

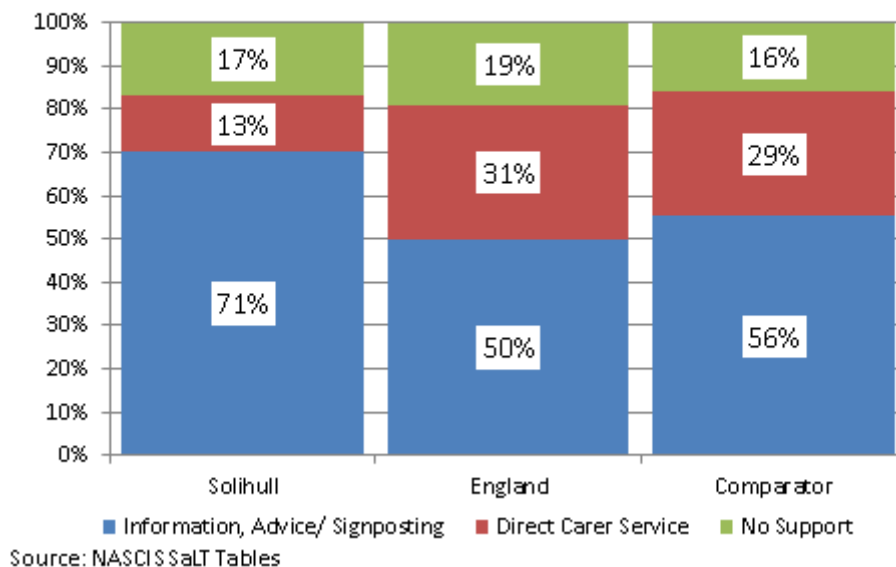
## Services for Solihull Carers

Services for Solihull carers are being delivered against a background of rising need in the population and reducing social care budgets, leading to more limited access to LA funded social care. For instance, in the five years to 2013/14 the number of Solihull residents aged 65+ receiving a social care package fell by -28%, despite a rise of 14% in the age group population.

In 2015/16 there were 960 adult carers in contact with Solihull council, as a proportion of the 18+ population this is lower than the England average (5.79 compared to 8.79 per 1,000).

In 2015/16 117 Solihull carers received a direct service through a Carers Direct Payment, with a further 679 receiving information or advice. Compared with England a relatively small proportion of Solihull carers in contact with social services in 2015/16 received a direct carers service (13% compared to 31%), although more received information or advice (71% compared to 50%).

## Carers in Contact with Social Services 2015/16



The number of carers receiving either a direct service or information or advice fell in 2015/16 (from 1,015 to 816), although the number benefitting from a respite service provided to the person they care for increased (from 180 to 220).

A large majority of Solihull carers in contact with social services in 2015/16 received a carer's assessment (81% compared to 66% across England as a whole). The majority of these assessments were conducted with the carer alone, although a third took place jointly with the cared for person.

## Carer Satisfaction with Solihull Services

Every two years Solihull Council has a statutory obligation to survey carers aged 18 and over, who are known to social services and caring for someone aged 18 or over. Preliminary results for 2016/17 show that, although a majority of Solihull carers (60%) are satisfied with the services they receive, the proportion has fallen over recent years. Similarly, fewer of those contributing to the latest survey found information & advice either easy to find or helpful.

Performance benchmarking the 2014/15 version of the survey shows that, in relation to carer satisfaction, Solihull has historically under-performed the national average and a group statistically similar Local Authorities.

<b>Carers Survey – Change in Key Measures in Solihull</b>				
	<b>2009/10</b>	<b>2012/13</b>	<b>2014/15</b>	<b>2016/17</b>
% Satisfied with the services they received	85%	70%	70%	60%
% Found information & advice Easy to find	72%	68%	61%	54%
% who found advice received useful	93%	89%	86%	81%
% Sufficiently involved & consulted about the care received by the person they care for	76%	67%	68%	66%
<i>Source: SMBC, Department of Health</i>				

## Consultation Feedback

Feedback from a 2014 consultation exercise with Solihull carers echoed many of the broad principles identified in national guidance and best practice evidence. There was a particularly strong message that recognition and respect should be at the heart of the relationship between carers and service professionals, with those contributing emphasising the importance of being involved and consulted in the decision making and care planning process. Other specific findings include:

- the need for flexible service delivery particularly in relation to highly valued respite services;
- the benefits of building and maintaining a relationship with an individual care professional (sole point of contact);
- information & advice that meets the needs of carers at different stages of the caring journey and that is delivered in a variety of formats;
- the important role that carer support groups play in disseminating information and providing emotional support;
- the importance of training for both carers and professionals;
- the benefits of long-term preventative planning, especially in relation to the long-term health effects of caring (e.g. carers health checks).

## Key Points in the Caring Journey

The caring experience is heightened at times of transition such as when someone becomes a carer, or when the condition of the cared for person deteriorates. Contact with services and the availability of high quality information and advice is particularly critical at these times.

Early identification of carers and adequate procedures for dealing with emergencies are particularly important in this context.

**Identification of carers:** In a Carers UK survey over half of respondents took over a year to recognise their caring role, with self identification taking longer for some specific groups such as parent and mental health carers. The impact can be substantial with many of those surveyed indicating that missing out on support had a range of negative financial, social and health effects.

Identifying young carers is a significant challenge, with particular problems reaching the very youngest carers (including some under the age of 5), as well as those caring for someone with a substance misuse problem or where there is domestic violence in the home. One study suggests that the Census under-estimated the true number by 75% and that as many as 1 in 12 up to the age of 18 have some form of caring responsibility. In Solihull this would equate to nearly 4,000 young carers (the Census recorded just 400 aged 0-15 years and a further 1,100 aged 16-24). In a local survey, 26% of year 8 and 10 pupils said they looked after someone on a regular basis but only 5% identified themselves as a young carer.

**Hospital Admissions and discharge:** There is evidence to suggest that a significant number of admissions are due to problems associated with the carer. For instance, one study tracking a sample of people over 75 years old who had entered the health and social care system, found that 20% were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent.

A Carers UK survey found 59% of carers dealing with an emergency admission felt that it was avoidable, with many citing a lack of carer support as the reason.

The hospital discharge process is an opportunity to ensure that carers have the support they need in the short-term and that they know how to find out more about their rights to support. However, Carers UK found that only 26% of carers surveyed were not consulted during the discharge process and a further 33% consulted only at the last minute.

## The Impact of Caring

**Health & Wellbeing:** National research shows that a caring role can have a negative impact on mental and physical health as well as emotional wellbeing. Those most at risk include women, elderly or very young people, those with pre-existing poor physical health, carers with arduous duties and those with few social contacts or support. In a Carers UK Survey 82% of those surveyed said that caring has a negative impact on their health.

Census data shows that those caring for 50 hours or more per week at far greater risk of poor health than those caring for fewer hours. In Solihull 13% of carers who provide 50+ hours of care per week state that their health is either bad or very bad compared to 4% among other carers.

The 2016/17 Carers Survey shows that 24% of Solihull Carers known to social services suffer from multiple health or disability conditions.

**Employment:** Census data shows that employment rates fall substantially among those who care for 50+ hours per week. This is consistent with the findings of the NHS Survey of



Carers in Households, in which 26% said that their caring role had affected their ability to take up or stay in employment, with this proportion rising significantly among those caring for 20 hours or more a week (40%).

However, a range of national research suggests that employers are increasingly recognising caring as a key issue for workforce recruitment and retention and introducing flexible working practices as a consequence.

**Financial burden:** The increased costs associated with caring (e.g higher basic household costs and expenditure on specialist equipment) allied to a reduced capacity to earn, mean that many carers face financial hardship. For instance, 45% of those surveyed in the State of Caring report say that they have cut back on food, with 44% cutting back on heating.

Carers UK attribute some of the financial hardship faced by carers to not getting the right information at the right time, with 42% of those surveyed feeling that they had missed out on financial support as a result of not getting the right information and advice early enough.

**Social Isolation and Personal Relationships:** Research from the US recognises that the experience of care giving can be a positive one. However, survey evidence from the NHS does show that caring can negatively impact on the carer's personal relationships, social life and leisure time, with those caring for 20 hours per week and those who live with the cared for person most affected.

This is echoed locally with 21% of Solihull respondents to the 2016/17 Carers Survey saying that they feel socially isolated and 21% saying that they don't do anything they value or enjoy.

## The Needs of Specific Carer Groups

All carers are individuals and as such have differing and diverse needs, although it is possible to identify specific types of challenges and needs across a range of carer groups.

**Young Carers:** National research suggests that young carers are at risk of a range of negative outcomes, such as poor educational attendance, social and emotional isolation, ill health and emotional distress that affect their life chances. It is estimated that as many as one-third of young carers are involved in excessive or inappropriate caring such as emotional support and intimate personal care.

A significant proportion of young carers aged 5 to 18 years taking part in a survey by the Solihull Carers Centre reported direct impacts on their own personal wellbeing such as feeling tired (69%), getting stressed (58%) and getting depressed (42%). Many also reported that their social relationships suffer (35% not able to go out with friends, 62% not able to have friends round). Although relatively few (8%) said that they miss school there is no doubt that school life is affected, with 35% missing homework/deadlines, 27% late for school.

**Young Adult carers:** National research notes that caring responsibilities create additional emotional and social pressures on those aged 16-24 years transitioning into adulthood, often negatively impacting on education, training and employment. For instance, an Audit Commission report highlights that young adult carers are more likely to be NEET (Not in

Education, Employment or Training) than their peers, weakening their employment prospects later in life.

**Older carers:** An NHS Survey shows that carers aged 65 and over are more likely to be a sole carer and live in the same house as the cared for person than younger age groups. Census data supports this with 37% of Solihull carers aged 65+ providing 50 hours or more of weekly care compared to just 16% among younger age groups.

Many older carers are subject to poor and deteriorating physical and mental health, with the effects of ageing often compounded by demands such as heavy lifting. Survey evidence also suggests that many neglect their own health, with one in three reporting that they had cancelled treatment or an operation because of their responsibilities.

Other common impacts include stress, worry over what will happen to the person they care for if they can no longer cope, financial pressures and social isolation. In the latter case many carers highlight the importance of day care and respite services, although survey evidence suggests that more than one third do not get breaks away from caring, and a further third get a break only once every 2–3 months or less.

**Carers of People with dementia:** It is estimated that two-thirds of UK people with dementia live in the community, which would equate to over 2,000 Solihull residents. The fact that only 44% of people with the condition have a diagnosis means that many carers will not receive appropriate support.

Alongside physical, health and social impacts, carers of people with dementia have to cope with challenging behaviour and acute emotional difficulties, especially when the care for person is a spouse or partner. There is no typical caring journey for this group, although the Carers Trust has identified a number of critical times for the carer such as the point of diagnosis, when the cared for person develops additional health or behaviour problems and when decisions have to be made about residential or end of life care.

**Sandwich carers:** National survey evidence highlights the extent to which people who care for a dependent child and an adult struggle to cope with conflicting responsibilities, with for instance, 42% reporting that they are struggling to breaking point. Negative impacts on family life and relationships as well as work and finances are common. In addition, many sandwich carers have to cope with feelings of guilt with, for example, four in 10 of those surveyed fearing that they are letting down their ageing parents or disabled loved ones.

## Best Practice and What Works Evidence

### **Best Practice Guidance**

A range of best practice guidelines from the Department of Health, the Department for Education, the Association of Directors of Adult Social Services (ADASS), the Royal College of General Practitioners (RCGP), the Children's Society and others set out principles for working with and for carers. Alongside this bottom up approach, there is a range of system wide guidance dealing with local partnerships, carer pathways and designing appropriate services and processes.

A number of common themes emerge, many of which were raised in consultation with Solihull carers. These are summarised under three broad headings:

### Working with Carers

- Where possible adopt a whole family approach, including child carers;
- Recognise carers as experts in the needs of the person they care for and what they need to continue in their caring responsibilities;
- Carers' needs are routinely reviewed alongside the needs of the person they support;
- Involve a diverse range of carers in local partnerships including the design of pathways and services;
- Reach out to carers not already in contact with services, which may require targeted engagement with specific hard to reach carer groups.

### Strategic Development and Commissioning Models

- The choice between developing an overarching strategy that addresses the needs of all carers and an integrated approach that addresses the needs of carers in every commissioning programme undertaken should be based on an understanding of local need (RCGP).
- Clearly defined carer pathways should be established with the ADASS guidance recommending three tiers:
  - A universal offer including advice and information;
  - Assessment, brokerage and advocacy to help people navigate the system;
  - Preventative and emergency support.
- Strengthening local partnership working between local authorities, the NHS (including hospitals, GPs and pharmacies), Health & Wellbeing Boards, Local Safeguarding Boards and the Voluntary & Community sector.
- Widening awareness and understanding of carers across the whole community, including services such as transport, leisure, education and housing, as well as among local employers and businesses.

### Services and Processes

- Importance of offering a varied portfolio of carers services that have been agreed across all partner organisations and that can be tailored to meet individual needs;
- Important to map existing local provision against national strategy for carers;
- Information sharing, for example on the choices, spending patterns and outcomes of carers with personal budgets, can help to inform commissioning and improve provision;
- Recognise the benefits of early identification and the importance of established referral mechanisms;
- Defined posts (e.g. carer champions) with carer awareness training should be embedded system wide;
- Explore joint commissioning opportunities for instance between children's and adults services.

## Research Evidence

Within the published research, the evidence relating to carer interventions is variable in strength and quality, with qualitative studies tending to show the most promising results.

One of the prevailing themes is the need for interventions to be appropriately tailored to the individual carer and carer group in order to maximise effectiveness. This suggests that robust local evaluation of interventions and services is required to ensure the service provision offered is suitable for the Solihull population. Key evidence relating to specific types of intervention are summarised below.

*Statutory Carer Assessments:* were found to help carers feel valued and supported. The quality of the assessments is of upmost importance. As such local authorities need to ensure that the process is adequately resourced and that staff have appropriate training.

*Personal Budgets/Direct Payments:* Some evidence a personal budget can have a positive impact on carer health and well being and that carers are happy with the help offered when deciding what services or support to purchase with their personal budget.

*Telecare and Telehealth:* Some evidence to suggest that by helping those with care needs maintain a degree of independence telecare can sustain carers in their caring role. It is found that stress levels among carers are reduced as a consequence of feeling less worried about the well-being and safety of the cared for person. Research suggests that impacts are not universal with those most benefitting likely to be carers of older people with specific conditions or those of adults with Learning Difficulties.

*Carers Breaks/Respite Care:* These are considered critical to the ability of some carers to continue caring, with particular benefits accruing from improved carer health and wellbeing. Offering a flexible variety of provision (e.g. day care, short stay residential care or sitting services) tailored to the needs of the carer and cared for person is important. It is found that investing in respite care results in savings resulting from reductions in unwanted (re)admissions, delayed discharges and residential care stays.

*Carer Support Groups:* The evidence suggests that these groups are a cost effective way of delivering a wide range of benefits, reduce social isolation and facilitate access to other services.

*Education and Training for Carers:* There is a substantial body of evidence suggesting that education and training programmes for carers are successful at building new knowledge and skills as well as having a positive impact upon emotional well-being.

# Section 1: Introduction

## About this Needs Assessment

This needs assessment is intended to provide some insight into the numbers of unpaid carers in Solihull and the extent and nature of local support services. National and local evidence shows that carers comprise a large number of people in many different situations. Consideration is therefore given to the personal circumstances of carers in terms of who they care for, the amount and type of care they provide and the impact that their caring role has on their health, employment situation, finances, quality of life and social relationships. Particular attention is paid to some groups of carers who face the most challenging circumstances including children, older carers, sandwich carers and those caring for people with dementia.

No one data source provides a definitive picture of the number of carers in Solihull or their personal circumstances. Self reported Census data from 2011 provides the comprehensive picture, particularly when used in conjunction with local data from the Solihull Carers Centre and Care First, and so this provides the basis for much of the analysis. A range of research literature, particularly from Carers UK, and national surveys provide much of the qualitative background for this report.

This report also looks at the increasing burden of care in the community, largely driven by Solihull's relatively older and rapidly ageing population, and seeks to assess the impact of this in terms of likely increases in the number of carers in the borough over the next five to ten years.

## National Context

At the time of the 2011 Census there were 6.5 million carers in the UK, representing an increase of 11% (622,000) compared with 2001. By 2015 it is estimated that this number had increased to 6.8 million<sup>1</sup>

Carers are not a static population and every year over 2.1 million adults become carers and almost as many people find that their caring responsibilities come to an end. This 'turnover' means that 3 in 5 people will be carers at some point in their lives<sup>2</sup>.

However, it should be recognised that nearly a third of carers do not recognise themselves as being a carer for up to five years. The Government report Recognised, Valued and Supported outlines some of the reasons why this may be the case:

*"A significant number of people with caring responsibilities do not readily identify themselves as carers. They understandably see themselves primarily as a parent, spouse, son, daughter, partner, friend or neighbour. In addition, the concept of caring is assumed but not recognised in some families in ethnic minority communities.*

*Many carers do not identify themselves as such until they have been caring for a number of years. This is understandable when the caring role develops gradually, for example with the onset of dementia. And when a family member or friend is suddenly in need of support, such*

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<sup>1</sup> Carers UK (2015): Valuing Carers

<sup>2</sup> Carers UK (2015): Facts About Carers

*as after a stroke, it can be difficult to find the time and energy to think through what the future may hold in terms of a caring role.”*

Carers UK research suggests that an ageing population, coupled with the direction of community care policy will require a 40% (2.6 million) increase in the number of UK carers by 2037 to 9 million<sup>3</sup>.

With families providing the bulk of care, the economic value of the contribution made by UK carers is estimated at £132 billion per year, almost double its value in 2001 (£68 billion)<sup>4</sup>. This is close to the total annual cost of health spending in the UK, which was £134.1 billion in the year 2014-2015. On this basis it can be estimated that carers save the public purse £2.5 billion per week.

## Government Policy

In June 2008 the Government published an updated national strategy for carers, "Carers at the heart of the 21st century, families and communities"<sup>5</sup>. This strategy identifies a carer as:

“A carer spends a significant proportion of their life providing unpaid support to family or friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.”

The strategy sets out the ten year vision for improving support for carers, which is a shared responsibility between central and local government, the NHS, the third sector, families and communities. The principles outlined in the ten year vision are that by 2018:

- carers will be treated with dignity and respect as expert care partners;
- carers will have access to the services they need to support them in their caring role;
- carers will be able to have a life of their own;
- carers will not be forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well;
- children and young people will be protected from inappropriate caring roles.

The 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.

In order to support the 10 year vision, the strategy includes a set of commitments, including better collection of data about carers' lives and to the continued inclusion of a question about carers in the Census.

The Coalition Government refreshed this strategy in Recognised, valued and supported: next steps for the Carers Strategy 2010<sup>6</sup> retaining these aims and including a series of actions necessary to support the best possible outcomes for carers and care recipients, including:

- Supporting early self-identification and involvement in local care planning and individual care planning;

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<sup>3</sup> Carers UK (2015): Facts About Carers

<sup>4</sup> Buckner L., Yeandle S., "Valuing Carers, – The Rising Value of Carers' Support," Carers UK (2016)

<sup>5</sup> "Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own", Department for Health, June 2008.

<sup>6</sup> Recognised Valued and Supported: Next Steps for the Carers Strategy, HM Government November 2010



- Enabling carers to fulfil their educational and employment potential;
- Personalised support for carers and those receiving care;
- Support carers to remain healthy.

Building on the national Carers Strategy of 2008 and the next steps update of 2010, the Government published the Carers strategy: actions for 2014 to 2016<sup>7</sup>, identifying the steps taken to improve awareness about the significant contribution that carers make and to improve support for carers in many spheres, including through Government legislation.

### **The Care Act (2014)**

The Care Act represents the most significant reform of care and support in more than 60 years. It will come into force in two stages April 2015 and April 2016. Central to the Act is the concept of wellbeing. First and foremost councils will now have a duty to consider the physical, mental and emotional wellbeing of the individual needing care. The Act reforms the law relating to care and support for adults and the law relating to support for carers, to make provision about safeguarding adults from abuse or neglect, to make provision about care standards, to establish and make provision about Health Education England. What it means for carers is their rights to achieve their day to day outcomes and access information.

The emphasis on prevention will mean that carers should receive support early on and before reaching crisis point. Information and integration of services should make it easier for individuals to access support and plan for their future needs. Adults and carers will have the same rights to an assessment on the appearance of needs. For carers this means that the previous requirement to provide 'substantial' and 'regular' care will be removed. The whole family will also be entitled to an assessment. Assessing what capabilities and existing resources a person may have needs careful consideration so that local authorities do not unduly rely on family and friends to provide care and support. After an assessment national eligibility criteria will be applied to the needs of the person. If a charge is incurred then the local authority must complete a financial assessment. All costs to the individual will be accrued in a 'care account'.

Following the principle that an individual is best placed to judge their own care and support needs the local authority must work with the individual and their carers to decide how needs should be met. Direct payments can be provided to an adult and to carers. Regulations on eligibility (due to be published) will be crucial in determining which needs and therefore which carers can receive support from the local authority.

### **The Children and Families Act (2014)**

Under the children and Families Act, local authorities are legally required to try and identify young carers and undertake a young carer assessment to identify their care and support needs, underpinned by an action plan, which can remain in place at the point of transition to young adult (16-25) and adult carers' services.

### **NHS Commitment to Carers**

The Department of Health set out in its mandate to NHS England 'that the NHS becomes dramatically better at involving carers as well as patients in its care'. In May 2014 they

<sup>7</sup> Carers Strategy Second National Action Plan 2014-2016, Department for Health, 2014

published NHS England's Commitment for Carers<sup>8</sup>, based on consultation with carers. The key themes were:

- Recognise me as a carer;
- Information is shared with me and other professionals;
- Signpost information for me and help to link professionals together;
- Care is flexible and is available when it suits me and the person I care for;
- Recognise that I may need help both in my caring role and maintaining my own health and well being;
- Respect, involve and treat me as an expert in care;
- Treat me with dignity and compassion.

Based on the emerging themes NHS England has developed 37 commitments around eight priorities, which include raising the profile of carers, education, training and information, person centred well co-ordinated care and partnership working.

## Data Sources

There are a number of data sources for carers, both local and national. None of these sources fully identify the number of carers and it is necessary to consider all together to get a clear picture. Each data source has its own shortcomings which are outlined below, although for the purposes of this report the 2011 Census is considered the most comprehensive source.

Identifying carers can be difficult when carers do not regard themselves as such. Even those who identify as being carers may be reluctant to engage with service providers or authorities due to a fear of interference by authorities. This is particularly noted with regard to children carers, where there is a fear that they will be taken into care if authorities found out they were taking care of a parent. Data sources may therefore under-report the size of the cohort.

### **Census 2011**

The 2011 Census provides the most comprehensive record of the number of carers in Solihull. However, as this is a self-reported measure it remains subject to the limitations set out above in terms of potential under-reporting.

### **Solihull Carers Centre**

The Solihull Carers Centre maintains a database of all young carers (aged 5-24 years) and adult carers (aged 25+), registered with the centre and who have been in contact within the last two years.

### **Solihull Care First**

Care First is the system used to record all of Solihull's adult social care clients and contacts. When social care service users are assessed they are asked whether they have a carer. This is a mandatory question and where identified Solihull Council will offer assessments and services for carers. Personal detail is recorded in the system, although this can be

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<sup>8</sup> NHS England's Commitment to Carers (2014). Accessed via:  
<https://www.england.nhs.uk/ourwork/pe/commitment-to-carers/>



limited as certain information (for example, age or ethnicity of the carer) is not mandatory. Reliable results are consequently not available for the BAME, parent and young carer groups. There are further issues in identifying carers through the system due to the way in which the system records them; the inherent problem is that the system was designed to monitor service users, not their carers.

### **Solihull Clinical Commissioning Group (CCG)**

All GP surgeries take part in the NHS Patient Survey which includes a question on caring responsibility. Patients aged 18+ that complete the survey indicate whether they have a caring responsibility. From this we have extrapolated the total number of adult carers registered at each Solihull CCG surgery.

It should be noted that this data covers all patients registered with a Solihull GP practice regardless of whether they are resident in the borough. This is significant because the patient CCG population is around 33,000 larger than Solihull resident population and will include significant numbers of patients who live in Birmingham and other Local Authority areas.

In addition, GP surgeries record whether patients have a caring responsibility on their patient register, although it is not clear to what extent this is uniformly applied and maintained across all practices.

## Section 2: Solihull Carers

### Self Identified Carers (Census)

In the 2011 Census a total of 24,113 Solihull residents identified themselves as providing unpaid care for a family member, friend or neighbour<sup>9</sup>. This equates to 11.7% of the population compared with the England average of 10.2%.

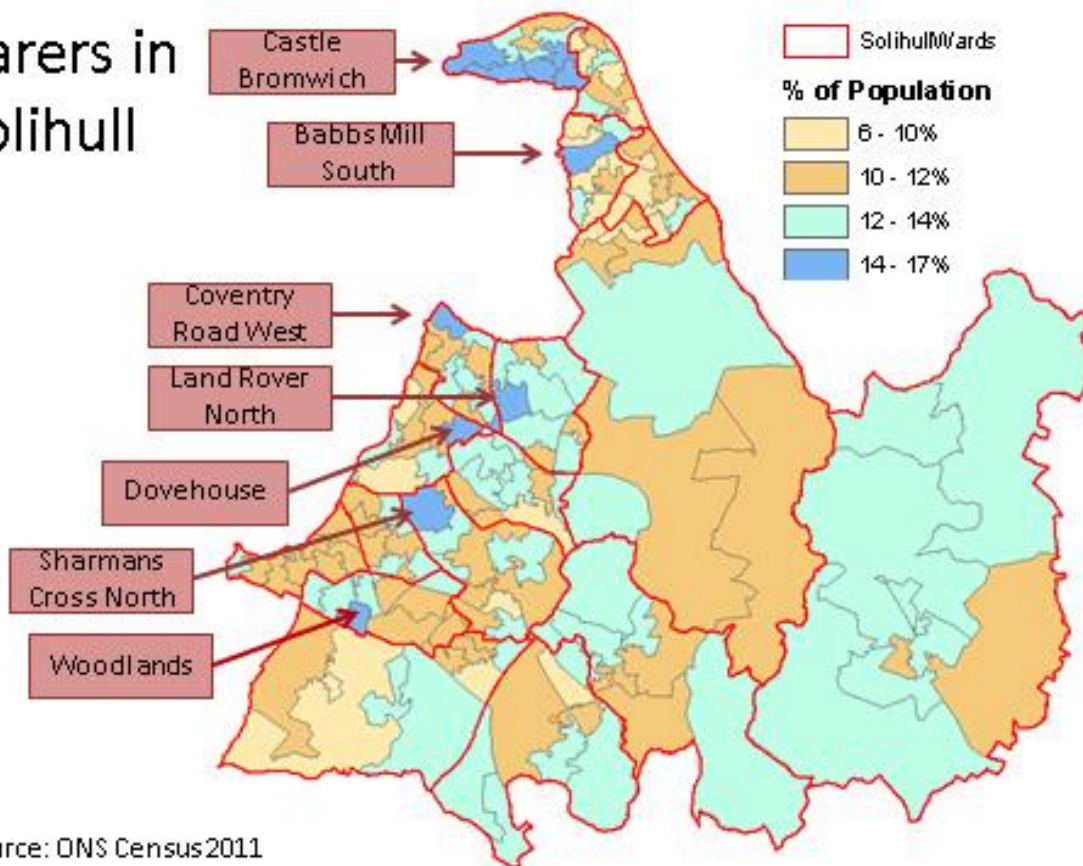
At a ward level there is a relatively narrow range in the proportion of the population who provide unpaid care, from over 14% in Castle Bromwich to around 10% in Chelmsley Wood.

	Carers all ages	
	Count	% population
Bickenhill	1,372	11.0%
Blythe	1,368	10.5%
Castle Bromwich	1,622	14.5%
Chelmsley Wood	1,264	10.2%
Dorridge & Hockley Heath	1,328	11.9%
Elmdon	1,471	12.2%
Kingshurst & Fordbridge	1,358	10.6%
Knowle	1,271	11.9%
Lyndon	1,627	12.0%
Meriden	1,451	12.4%
Olton	1,416	11.6%
St Alphege	1,613	11.9%
Shirley East	1,404	12.0%
Shirley South	1,508	12.5%
Shirley West	1,360	11.4%
Silhill	1,361	11.5%
Smith's Wood	1,319	10.6%
<i>Source: ONS Census 2011</i>		

The map below shows the distribution of carers at a Lower Super Output Area (LSOA) level. Alongside five LSOA neighbourhoods in Castle Bromwich there are six LSOAs in the rest of the borough where more than 14% of the population have a caring role: Babbs Mill North (Kingshurst & Fordbridge ward), Coventry Road West (Lyndon), Land Rover North (Elmdon), Dovehouse (Olton), Sharmans Cross North (St Alphege) and Woodlands (Shirley South).

<sup>9</sup> The Census defines care as being due to either long-term physical or mental ill-health/disability or due to problems associated with old age.

# Carers in Solihull



## Solihull Carer Profile (Census)

The 2011 Census provides some limited profile data around age, gender, ethnicity and hours of care provided. Information relating to carers health and employment is detailed in section 5 of this report (The Caring Experience).

58% of Solihull carers are women (13,928) and 42% male (10,176). In total 13% of all women provide unpaid care compared to 10% of all men. Working age women are much more likely to have a caring role, although proportionally more men over the age of 65 years provide unpaid care (17% compared to 14%).

Solihull Carer Population by Age and Gender				
Age	Number		% Population	
	Female	Male	Female	Male
0-24 Years	863	651	3%	2%
25-49 Years	4,696	2,905	14%	9%
50-64 Years	5,292	3,762	26%	19%
65 Years+	3,077	2,858	14%	17%
All Ages	13,928	10,176	13%	10%

Source: ONS Census 2011

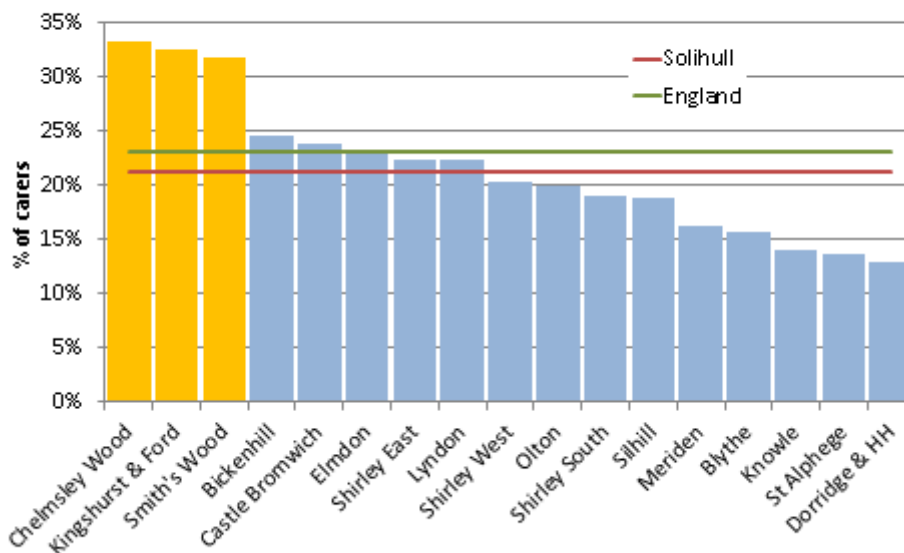
67% of all Solihull carers provide 1 to 19 hours of care per week, 12% 20 to 49 hours and 21% 50 hours+. This split is broadly in line with the England average.

Carer Population by Number of Hours of Care Provided			
Weekly Hours	Solihull Count	% of all carers	
		Solihull	England
1 to 19 Hours	16,084	67%	64%
20 to 49 Hours	2,896	12%	13%
50+ Hours	5,133	21%	23%
All Carers	24,113		

Source: ONS Census 2011

At a ward level a higher proportion of carers in the North Solihull regeneration wards (33%) provide 50 hours or more of care per week than elsewhere in the borough (19%).

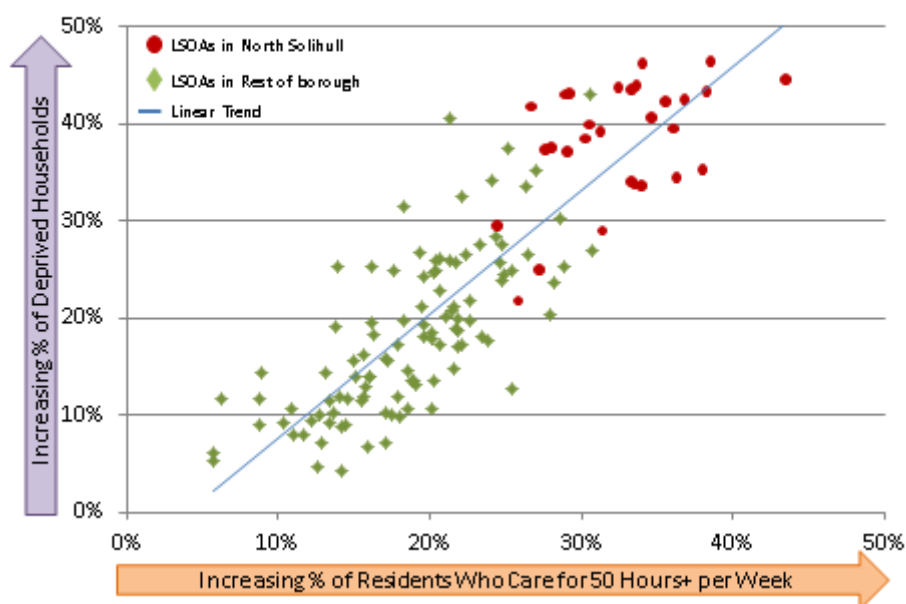
### Carers Caring for 50+ Hours per Week



Source: ONS Census 2011

The increased tendency for carers in the most deprived parts of the borough provide to care for 50 hours or more per week is also clearly evident at an LSOA neighbourhood level. As the chart below shows more than 30% of carers provide 50+ hours of care in most neighbourhoods in North Solihull, as well as in some of the more deprived areas of the south such as Hobs Moat North, Olton North and Cranmore South. In the least deprived neighbourhoods in south Solihull this proportion falls to under 10%.

## Link Between Deprivation and Caring for 50 Hours+ per Week in Solihull



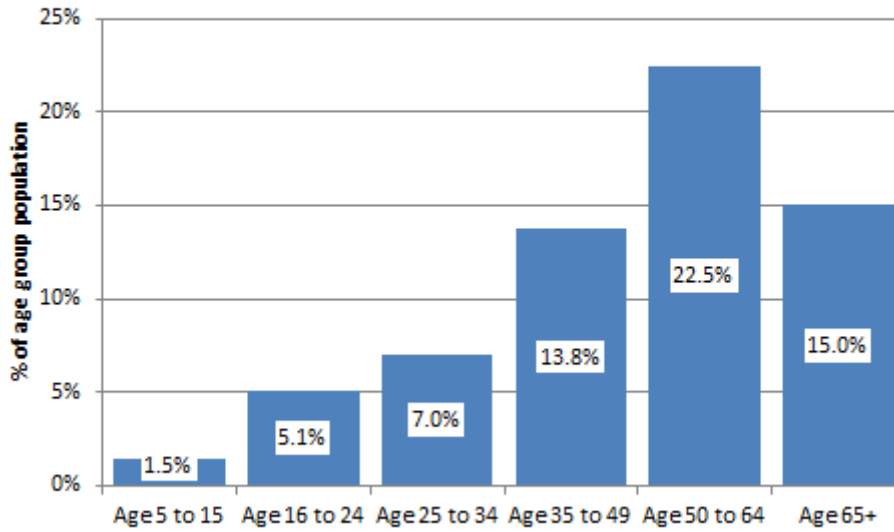
A large majority of Solihull carers are aged 35 and over (88% compared to 84% across England), with a quarter aged 65 years+.

Carer Population by Age of Carer			
Age of Carer	Solihull Count	% of All Carers	
		Solihull	England
Age 0 – 15 Years	404	1.7%	2.1%
Age 16 – 24 Years	1,111	4.6%	5.6%
Age 25 – 34 Years	1,502	6.2%	8.7%
Age 35 – 49 Years	6,102	25.3%	26.2%
Age 50 – 64 Years	9,056	37.6%	35.5%
Age 65+	5,938	24.6%	22.0%

Source: ONS Census 2011

As the chart below shows, up to retirement age the chances of being a carer increase with age, with those aged 50-64 years the most likely to be a carer (23% of this age group in Solihull).

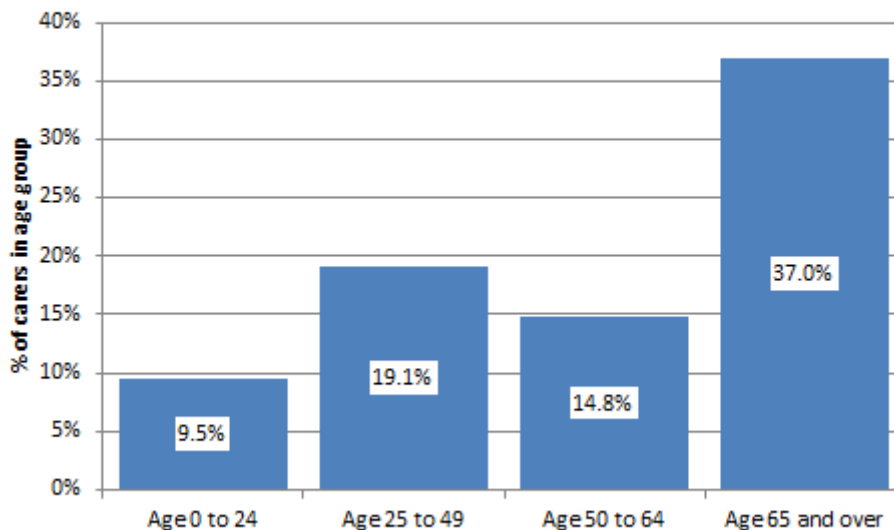
### Proportion of Solihull Population Providing Unpaid Care by Age Band



Source: ONS Census 2011

The likelihood of being a carer falls slightly after the age of 65 (15% of this age group). However, among those who do provide care those aged 65+ are significantly more likely to provide care for at least 50 hours per week than younger carers. In total there are nearly 2,200 Solihull residents aged 65+ in Solihull who provide 50 hours or more of care per week, equating to 37% of all carers in this age group. This is more than double the proportion among those under 65 years (16%).

### Proportion of Solihull Carers Providing Unpaid Care for 50 Hours+ per Week by Age Band



Source: ONS Census 2011

92% of Solihull carers are white, with those from an Asian/Asian British background the next largest group. In total 12% of the white population identify themselves as a carer compared

to 8% from a Black or Asian Minority Ethnic Group (BAME), with the latter ranging from 10% among those from a Black/Black British background to 6% among the Mixed Race population. These differences, which are also apparent nationally, are likely to reflect differences in age structure among different ethnic groups. For instance, 39% of Solihull's white population is aged 50 or over whereas among the mixed race population it is just 7%. This is significant because individuals are more likely to be a carer later in life.

<b>Carer Population by Ethnic Group</b>			
Ethnic Group	Solihull Count	% Ethnic Group Population	
		Solihull	England
White	22,240	12%	11%
Mixed Race	248	6%	6%
Asian/Asian British	1,190	9%	9%
Black/Black British	322	10%	7%
Other ethnic group	113	9%	7%
<b><i>BAME Total</i></b>	1,873	8%	8%
All Ethnic Groups	24,113	12%	10%

*Source: ONS Census 2011*

### **National Carer Profile Applied to Solihull Population**

The 2009/10 NHS Survey of Carers in Households provides some profile data not available through the Census. Applying characteristics from this national profile to Solihull's Census carer population provides some indicative local figures.

83% of those survey cared for one person, 14% care for two people and 3% care for three or more people. Applying these percentages to the Solihull's carer population from the 2011 Census would mean that a total of around 4,100 Solihull residents care for two or more other people.

Half of all those surveyed care for someone aged 75 years and over, with children aged 16 and under representing just 8% of the total. Applying this to Solihull suggests that around 12,000 people in the borough care for someone aged 75+ and around 1,900 for a child aged under 16.

<b>Age of Cared for Person</b>	<b>% of Carers Surveyed<sup>1</sup></b>	<b>Applied to Solihull Carers Population<sup>2</sup></b>
Under 16	8%	1,929
16-34	7%	1,688
35-44	5%	1,206
45-54	7%	1,688
55-64	11%	2,652
65-74	13%	3,135
75+	50%	12,057

Sources:  
<sup>1</sup>NHS Survey of Carers in Households 2009/10  
<sup>2</sup>ONS Census 2011

Caring for a parent is the most common (33%) followed by spouse/partner (26%) and child (13%), with other relatives accounting for 18% and friends or neighbours 9%.

Age of Cared for Person	% of Carers Surveyed <sup>1</sup>	Applied to Solihull Carers Population <sup>2</sup>
Parent	33%	7,957
Spouse/partner	26%	6,269
Child	13%	3,135
Friend or neighbour	9%	2,170
Parent in law	7%	1,688
Other relative	7%	1,688
Grand-parent	4%	965
Other	1%	241

Sources:  
<sup>1</sup>NHS Survey of Carers in Households 2009/10  
<sup>2</sup>ONS Census 2011

In terms of the condition of the cared for person, the most common is physical disability (58%), followed by a long standing illness. Less common, but also significant are mental health problems (13%), learning disability (11%) and dementia (10%).

Age of Cared for Person	% of Carers Surveyed <sup>1</sup>	Applied to Solihull Carers Population <sup>2</sup>
A physical disability	58%	13,986
Long-standing illness	37%	8,922
Sight or hearing loss	20%	4,823
Problems connected to ageing	17%	4,099
A mental health problem	13%	3,135
A learning disability or difficulty	11%	2,652
Dementia	10%	2,411
Terminal illness	4%	965
Alcohol or drug dependency	1%	241
Other	1%	241

Sources:  
<sup>1</sup>NHS Survey of Carers in Households 2009/10  
<sup>2</sup>ONS Census 2011

## Carer Population Projections

Carers UK estimate that, a rapidly rising older population will mean that the number of Carers in the UK will rise by 40% between 2015 and 2037<sup>10</sup>.

The pressures that underpin the Carers UK projection are echoed in similar work by Age UK<sup>11</sup>, which uses data from a national household survey (Understanding Society) to estimate growth in the carers population. The Age UK report notes that the proportion of people who provide unpaid care for family and friends has increased slightly in recent years (from 16.6% of the population in 2011 to 17.8% in 2015). However, due to overall population growth, the

<sup>10</sup> Carers UK (2015): Facts About Carers

<sup>11</sup> Age UK (2017): Health and Care of Older People in England 2017



total number of carers is in going up much more quickly, with the report identifying two key factors:

- The rapidly rising older population, particularly those aged 85+;
  - Nationally, the numbers of people aged 85+ increased by almost a third over the last decade and will more than double over the next two decades;
- The declining provision of formal care services for this group;
  - There has been a £160 million cut in total spending in real terms on older people's social care in the five years to 2015/16;
  - The percentage of our older population receiving social care support fell from 15.3% in 2005/06 to 9.2% in 2013/14;
  - There are now nearly 1.2 million people aged 65+ who don't receive the help they need with essential daily living activities. This represents a 48% increase since 2010.

In order to estimate future growth in the numbers of carers in Solihull it is important to consider the age of the cared for person and the likely growth in these age groups. The table below shows the NHS Carers Survey breakdown for the age of the cared for person; 50% of carers care for someone aged 75+, in Solihull this would mean that, based on the 2011 Census figures, 12,057 individuals in Solihull care for someone aged 75+.

The Solihull population increased by 2% between 2011 and 2015 and is projected to increase by a further 6% by 2025. This projected increase varies widely by age group, with the numbers of older people increasing by more than younger age groups (e.g. the number of residents aged 75+ is projected to increase by +33% between 2015 and 2025).

<b>Age of Cared for Person</b>	<b>% of Carers<sup>1</sup></b>	<b>Number of Solihull Carers in 2011<sup>2</sup></b>	<b>Age Group Population Change 2011-2025<sup>3</sup></b>
Under 16	8%	1,929	+6%
16-34	7%	1,688	-21%
35-44	5%	1,206	-1%
45-54	7%	1,688	-13%
55-64	11%	2,652	+16%
65-74	13%	3,135	+11%
75+	50%	12,057	+42%

Source:

<sup>1</sup>NHS Survey of Carers in Households 2009/10

<sup>2</sup>ONS Census 2011

<sup>3</sup>ONS Sub-National Population Projections

Applying these age group population projections to the number of carers in each age group provides a crude number of total carers in Solihull by 2025. This does not take into account any possible increases in the number of people who care for more than one person or a reduction or any improvements in the overall health of the population (particularly those allowing older people to retain mobility and independence). On this basis the number of carers in Solihull is projected to increase by +23% (+5,600) between 2011 and 2025 (from 24,100 to 29,700). The table below shows this change by the age group of the cared for person.

Age of Cared for Person <sup>1</sup>	Number of Carers <sup>2</sup>		Change 2011-2025 <sup>3</sup>	
	2011	2025	Number	%
Under 16	1,929	2,049	+120	+6%
16-34	1,688	1,332	-356	-21%
35-44	1,206	1,189	-16	-1%
45-54	1,688	1,464	-224	-13%
55-64	2,652	3,079	+427	+16%
65-74	3,135	3,466	+332	+11%
75+	12,057	17,067	+5,010	+42%
Total	24,113	29,646	+5,533	+23%

Sources:  
<sup>1</sup> NHS Survey of Carers in Households 2009/10  
<sup>2</sup> ONS Census 2011  
<sup>3</sup> Calculated Solihull Observatory

The table below shows this analysis projected through to 2035. By this point it is estimated that there will be over 33,000 Carers in Solihull, 36% more than in 2011. This level of increase is broadly consistent with work carried out by Carers UK which estimated a national increase of 40% in the number of UK Carers by 2037.

Year	Projected Increase in Solihull Carers		
	Solihull Carers	Increase Compared with 2011	
		Number	%
2011	24,100		
2017	25,600	1,500	6%
2020	27,000	2,900	12%
2025	29,600	5,500	23%
2030	31,400	7,300	30%
2035	33,100	9,000	37%

Sources: ONS/Solihull Observatory

These projections are also consistent with Solihull's ageing population. A sharp rise in the number of older people (particularly those aged 85+) will increase the number of people in the borough with a care need. This is described more fully in Appendix 1.

An important caveat is provided by Age UK, with their analysis questioning the extent to which families have the capacity to deliver the additional informal care requirements outlined above. They cite changing family structures, greater geographical dispersal, demands of the workplace (likely to increase with rising State Pension age) and a reliance on older carers, often experiencing poor health themselves as potentially limiting factors, concluding that this all points towards families and communities reaching the practical limits of the care they are able to provide in the context of a rapidly ageing population.

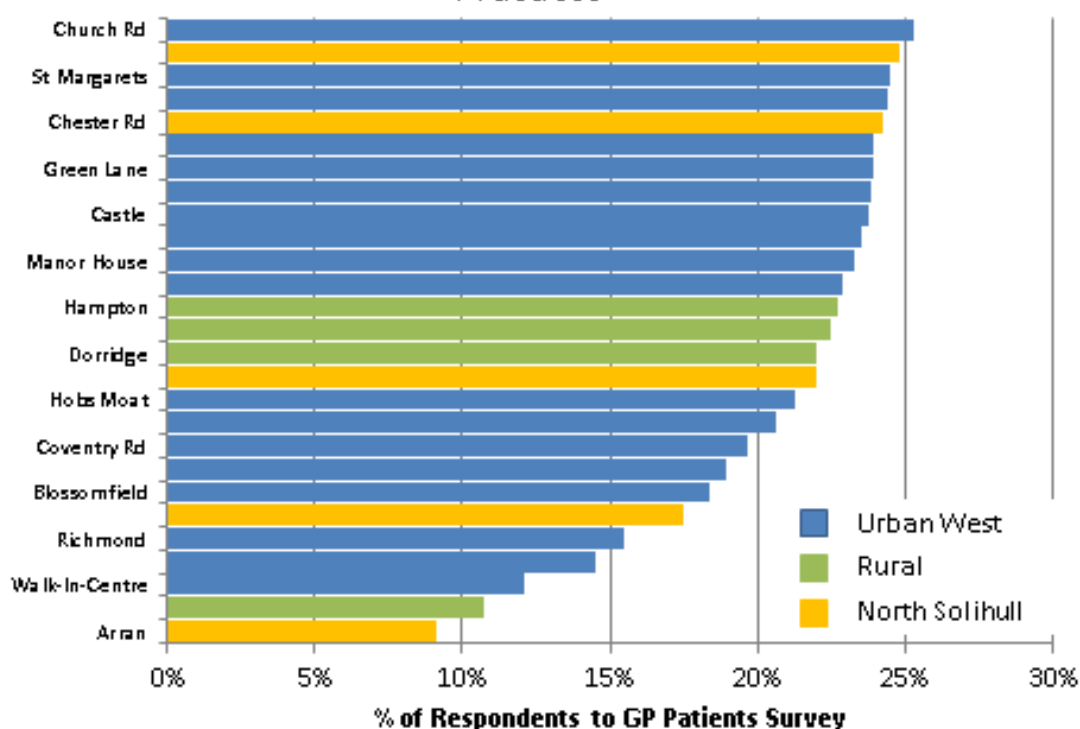
## Carers Known to GPs

22% of patients aged 18 and over registered at a Solihull Clinical Commissioning Group (CCG) GP who responded to the GP patient survey said that they had a caring responsibility<sup>12</sup> compared to the England average of 18%. This equates to just over 42,000 patients aged 18 and over on the Solihull CCG practice register. The proportion who indicated in the GP patient survey that they had a caring responsibility ranged from 25% of patients at Church Road Surgery to 9% at Arran Medical Centre.

	% aged 18+ with Caring Responsibility	Patients Aged 18+ with Caring Responsibility
Church Road Surgery	25%	2,323
Croft Medical Centre	25%	2,002
St.Margarets Medical Practice	25%	1,409
Bernays & Whitehouse Group Practice	24%	3,930
Chester Road Surgery	24%	695
Haslucks Green Medical Centre	24%	1,309
Green Lane Surgery	24%	1,094
Gps Healthcare	24%	7,720
The Castle Practice	24%	2,236
Monkspath Surgery	23%	2,257
Manor House Lane Surgery	23%	1,884
Parkfield Medical Centre	23%	606
Hampton Surgery	23%	521
Balsall Common & Meriden Group Practice	23%	2,307
Dorridge Surgery	22%	1,950
Kingshurst Medical Practice	22%	1,089
Hobs Moat Medical Centre	21%	1,742
The Jacey Practice	21%	1,577
Coventry Road Practice	20%	640
Northbrook Health Centre	19%	1,633
Blossomfield Surgery	18%	347
Bosworth Medical Centre	18%	1,225
Richmond Medical Centre	15%	664
Grafton Road Surgery	15%	328
Solihull Healthcare & Walk-In-Centre	12%	224
Arden Medical Centre	11%	375
Arran Medical Centre	9%	352
<i>Source: Public Health England, GP Patients Survey 2015-16</i>		

<sup>12</sup> Respondents to the GP Survey were asked: "Do you look after, or give any help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill health / disability, or problems related to old age?"

## Patients Aged 18+ with Caring Responsibilities at Solihull CCG GP Practices



Source: Public Health England, GP Patients Survey 2015/16

## Adult Carers Known to Solihull Carers Centre

The Solihull Carers Centre has a total of 1,886 active<sup>13</sup> adult carers aged 25+, which represents around 8% of all those identified within the Census. As the table below shows 60% of carers known to the Carers Centre are aged 25 to 64 years and 38% are aged 65+. The age distribution of carers known to the Carers Centre is slightly more skewed to those aged 65+ than the Census.

Adult Carers known to Carers Centre		
	Carers	% Total
25 - 64	1,125	60%
65 - 84	590	31%
85+	137	7%
Not known	34	2%
Total	1,886	

Source: SMBC and Solihull Carers Centre

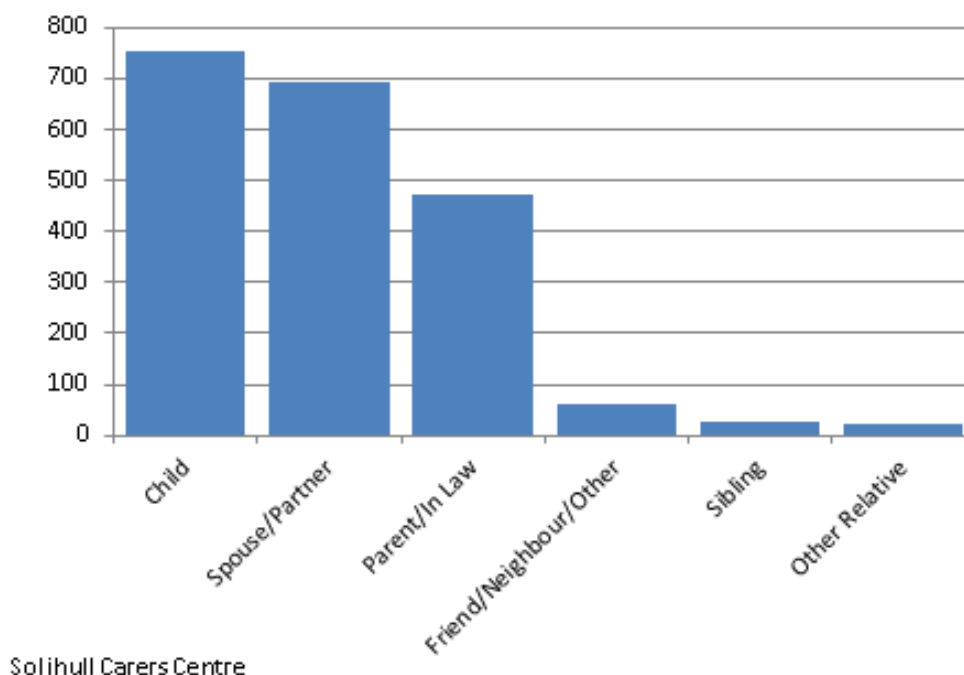
Where ethnicity is known, around 93% of adult carers registered with the Carers Centre are White and 7% from a Black or Minority Ethnic (BAME) background. This is broadly the same distribution as the Census.

<sup>13</sup> Registered and in contact within the last 2 years.

	Adult Carers known to Carers Centre	
	Carers	% Total (known)
White	1,686	93%
Mixed Race	27	1%
Asian/Asian British	82	5%
Black/Black British	20	1%
Not Stated	71	
All Known Ethnicity	1,815	
Total	1,886	
<i>Source: SMBC and Solihull Carers Centre</i>		

The majority of adult carers registered with the Carers Centre care for a family member, with around 3% caring for a friend, neighbour or other. The most common relationships are: child (36%), spouse/partner (33%) and parent/in law (22%). The proportion of Carers Centre carers caring for a child is higher than that identified in the NHS Survey of Carers in Households (36% compared to 13%), whereas the proportion caring for a parent/in law is lower (22% compared to 40%).

### Relationship Between Carer and Cared for Person



Just over a third of those cared for by a carer registered with the Carers Centre are identified as having a physical disability, with learning disabilities (29%) and mental health (21%) the next most common conditions. Carers known to the Carers Centre appear more likely to be caring for someone with a Learning Disability than nationally (29% compared to 11% of those in the NHS Survey of Carers in Households). Those caring for someone with a physical or sensory disability, for someone with a long-standing illness or who is frail/elderly appear under-represented.

<b>People Cared for by Adult Carers Known to Carers Centre</b>		
Condition of Cared for Person	Cared for	% Total
Physical Disabilities	709	34%
Learning Disabilities	605	29%
Mental Health	452	21%
Long Term Illness	219	10%
Frail/Elderly	67	3%
Sensory	60	3%
Addiction	1	0%
All those care for	2,113	
<i>Source: SMBC and Solihull Carers Centre</i>		

## Carers in Receipt of Carers Allowance

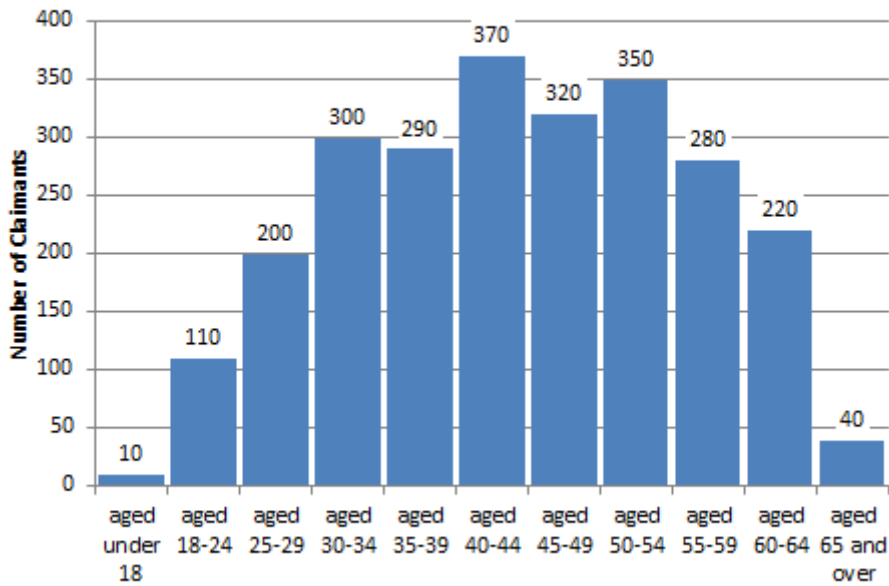
Carer's Allowance is the main benefit available to carers. It is applied for directly by the individual and is therefore independent of any NHS or Solihull social care services. Whilst NHS or SMBC can inform and signpost individuals to the benefit it is the responsibility of that individual to apply and if they meet the criteria they receive it.

To be eligible for the benefit, the person being cared for must be in receipt of a qualifying disability benefit. This means that the carer needs only fill in an additional form and does not need to approach a new agency, which is often a barrier to accessing other services.

Additional criteria are that the applicant must look after another person for at least 35 hours per week and they must be over 16 years of age. The Department of Work and Pensions (DWP) figures will therefore not account for young carers and those who care for others on a less full time basis. As such, this source is unlikely to inform the real number of carers in an area. However, taken alongside other data sources it may highlight the numbers of carers eligible for financial support and not receiving it, which is important in targeting support.

The latest data (May 2016) from the DWP shows that there were 2,480 individuals in Solihull in receipt of a Carers Allowance (1,930 female, 550 male). Like England as a whole more than three quarters of these individuals (77%) are aged between 30 and 59 years of age, with just 2% aged 65+ and 5% below the age of 25.

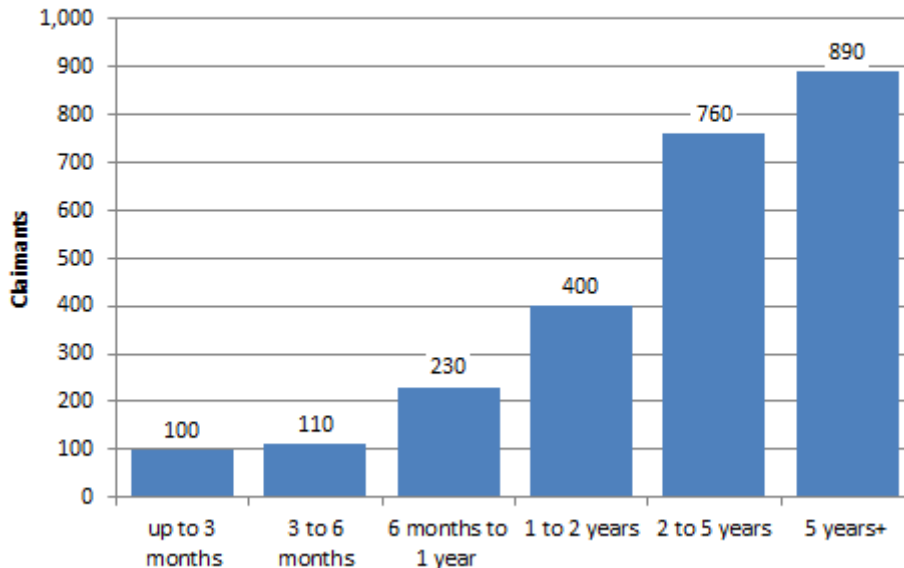
### Solihull Carers in Receipt of a Carers Allowance May 2016



Source: DWP

67% of all claimants in Solihull have been claiming for two years or more, with nearly 36% claiming for five years and over.

### Solihull Claimants of Carers Allowance by Duration of Claim



Source: DWP

In May 2013 Carers UK used DWP to estimate the number of UK carers who were eligible for, but not claiming, Carers Allowance.<sup>14</sup> Applying this same methodology to Solihull, suggests that in May 2016 1,335 eligible Solihull carers were not claiming, representing 35%

<sup>14</sup> Carers UK (2013): Estimates on the Number of Carers Missing Out on Carer’s Allowance

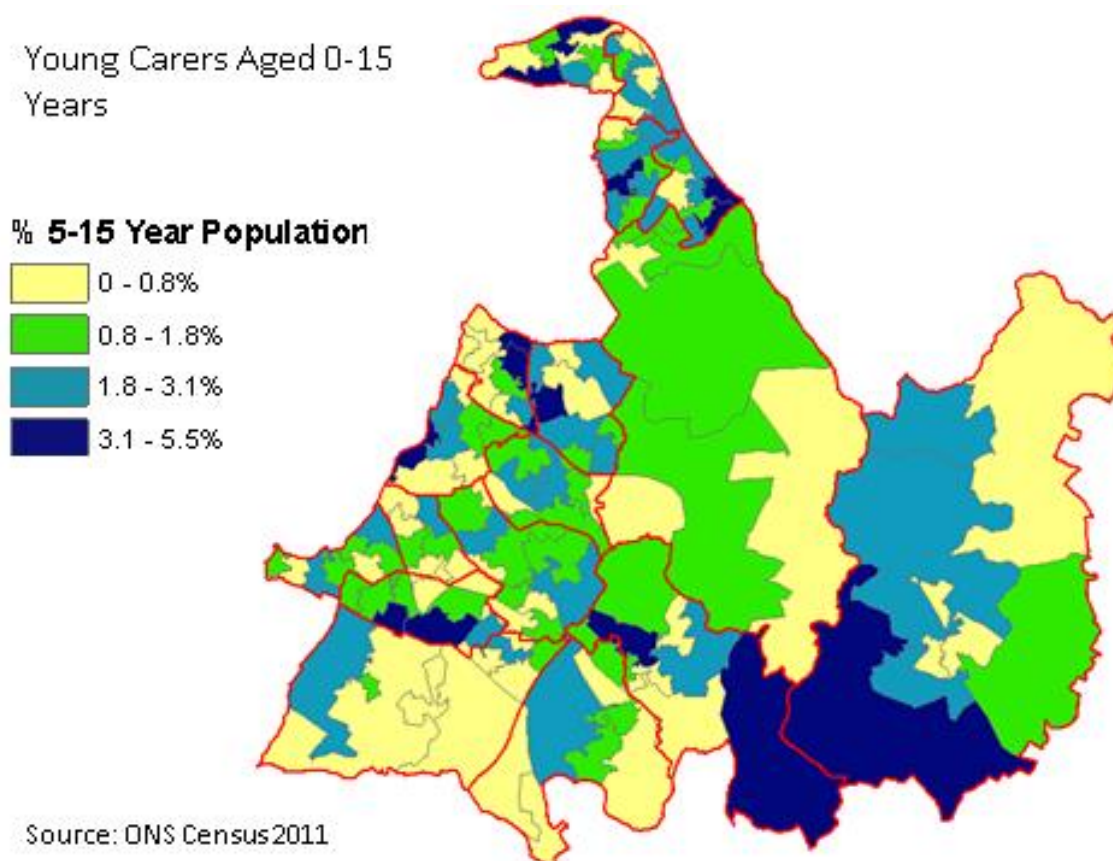


of all those eligible. Based on average weekly payments, this would mean that annually Solihull carers are missing out on around £42.8 million in unclaimed benefits.

## Solihull Young Carers

The Census is the most complete source for identifying the total number of carers in the borough, although it should be remembered that Census returns are completed by parents and not children and that particular caution should be used when using it as a source for identifying young carers. Problems with identifying young carers are considered in more detail under the heading of young carers in section 6 of this report (The Caring Experience).

The 2011 Census identifies a total of 404 carers under the age of 15 in Solihull which can be expressed as 1.5% of the population aged between 5 and 15 years<sup>15</sup>, although the proportion who provide care among older children in this age group is likely to be higher. This is slightly below the England average (1.7%), but rises to more than 4% in a number of Solihull's LSOA neighbourhoods.



There are currently 545 young carers aged 5 to 24 years known to the Carers Centre (those that are registered and have been in contact in the last two years). Slightly more of these young carers live in the wider North Solihull area of Chelmsley Wood, Kingshurst & Fordbridge, Smith's Wood and Castle Bromwich (282) than the South of the borough (211), suggesting that the Carers Centre reach is more comprehensive in the North (according to the Census just 35% of carers aged 0-24 live in the wider North Solihull area).

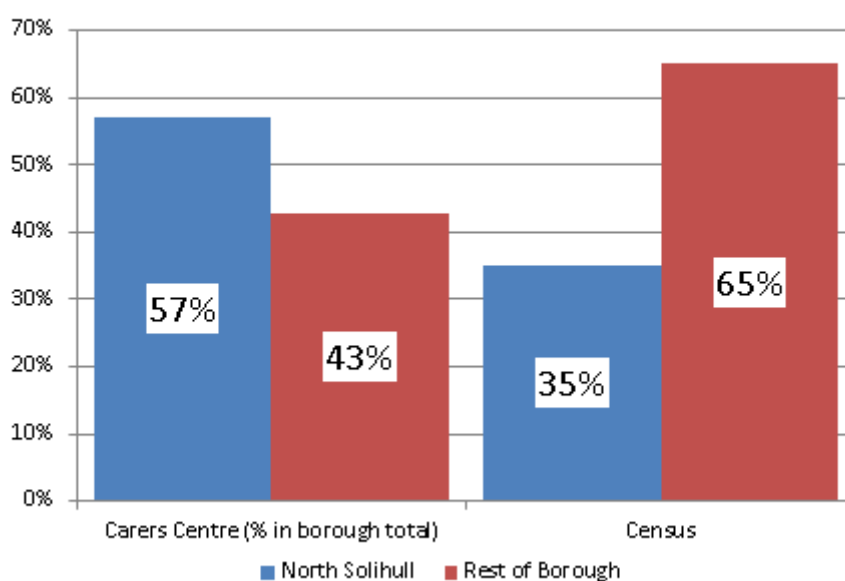
<sup>15</sup> It is assumed that children under the age of five are not able to fulfil a caring role



<b>Where Young Carers Aged 0-24 Years Known to Carers Centre Live</b>			
	Count	% Total	% In Borough Total
North Solihull	282	52%	57%
Rest of Borough	211	39%	43%
Out of Borough	51	9%	
Unknown	1	0%	
<b>Total</b>	<b>545</b>		

*Source: SMBC and Solihull Carers Centre*

### Where Solihull Young Carers Aged 0-24 Years Live



The detailed breakdown of the young carers known to the carers centre shows that 33% are below secondary school age (5-10 years), 41% are aged 11-15 years and 25% are aged 16 to 24.

<b>Young Carers Known to Carers Centre</b>		
Age of Carer	Count	% Total
5-10 Years	178	33%
11-15 Years	226	41%
16-18 Years	93	17%
19-24 Years	45	8%
Unknown	3	1%
<b>Total</b>	<b>545</b>	

*Source: SMBC and Solihull Carers Centre*

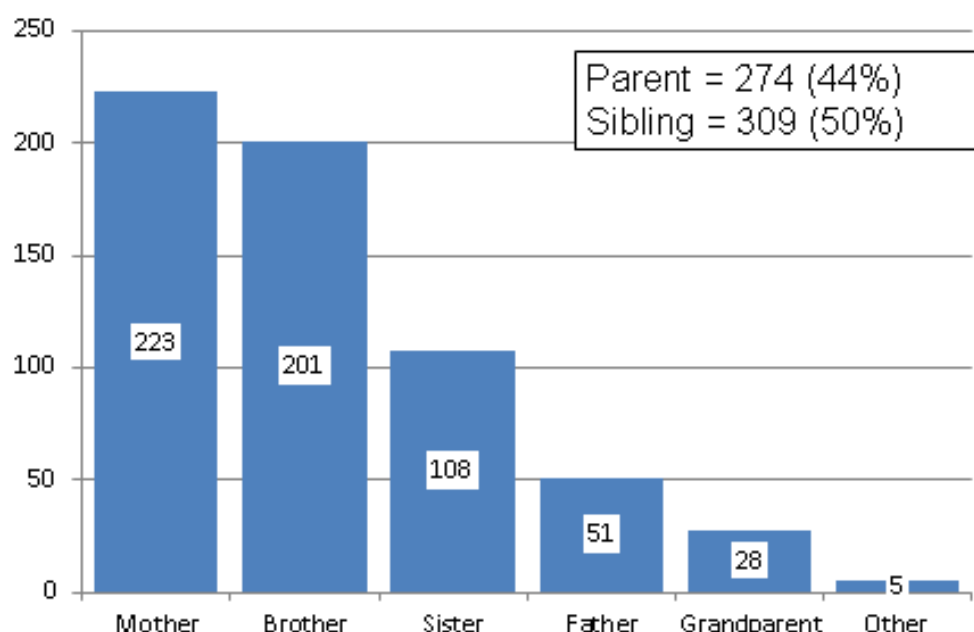
Where ethnicity is known 89% (465 individuals) of the young carers known to the Carers Centre are White British, with 11% (57 individuals) from a Black or Asian Minority Ethnic (BAME) background.

Ethnicity of Young Carers Aged 0-24 Years Known to Carers Centre			
Ethnic Group	Count	% Total	% Known Ethnicity
White	465	85%	89%
Mixed Race	22	4%	4%
Asian/Asian British	22	4%	4%
Black/Black British	7	1%	1%
Any Other ethnicity	6	1%	1%
Unknown	23	4%	
Total	545		

Source: SMBC and Solihull Carers Centre

A number of these identified young carers care for more than one person, with most caring for either one or both of their parents (mother 223, father 51) or for one or more sibling of their siblings (201 brother, 108 sister).

### Relationship Between Young Carer and Cared for Person



Solihull Carers Centre

Of those where the condition is known, around 46% of those cared for by a young carer registered with the Carers Centre are identified as having a physical disability, with learning disabilities (28%) and mental health (23%) the next most common conditions. This is broadly similar to the pattern identified among adult carers known to the Carers Centre.

<b>People Cared for by Young Carers Known to Carers Centre</b>			
Condition of Cared for Person	Cared for	% Total	% Where condition Known
Physical Disabilities	286	46%	47%
Learning Disabilities	168	27%	28%
Mental Health	139	22%	23%
Substance Abuse	16	3%	3%
Unknown	10	2%	
All those care for	619		
<i>Source: SMBC and Solihull Carers Centre</i>			

## Section 3: Services for Solihull Carers

### Social Care Context

Before describing services provided specifically for carers in Solihull it is worth understanding the broader social care context.

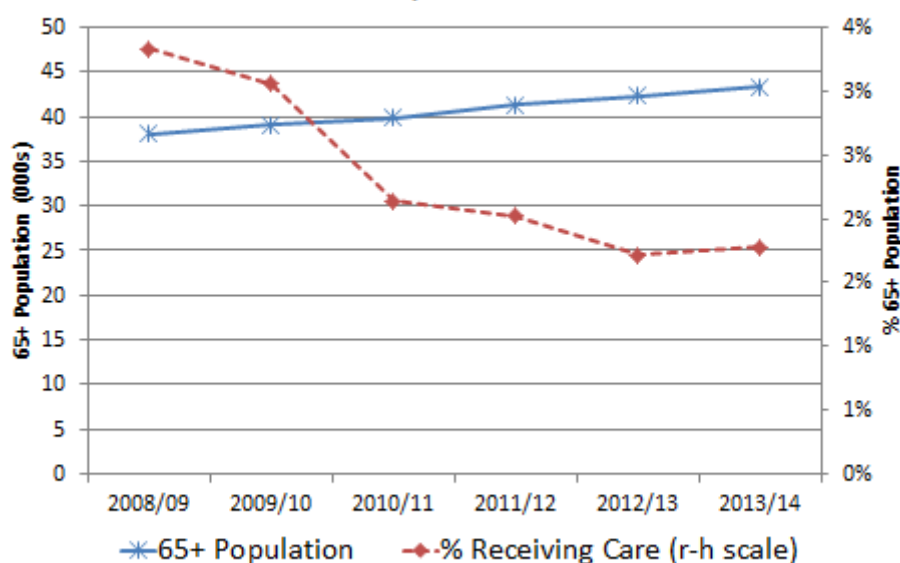
The provision of Local Authority funded social care is facing the twin pressures of rising demand from an ageing population with increasing care needs (described in appendix 1 of this report) and reducing budgets. In the case of the latter an Age UK<sup>16</sup> report estimates that net expenditure on social care from local authority funds (excluding transfers from the NHS) fell by 21% in real terms in the five years to 2015/16.

This squeeze on social care expenditure has, over recent years, contributed to a fall in the number of people receiving Local Authority funded social care. This is most evident among the older population aged 65 and over. The number of people aged 65+ receiving council funded social care in Solihull fell by 28% (-1,490) in the five years to 2013/14 (from 5,300 to 3,810), with the majority of this fall relating to those receiving a based community service. During this period the Solihull 65+ population rose by a total of 14% (including an increase of 26% in those aged 85+, the group most likely to require care). Similar trends are evident across England as a whole.

	<b>Local Authority Funded Social Care in Solihull</b>			
	Annual Count		Change 2008/09 – 2013/14	
	2008/09	2013/14	Number	%
All Service Users Aged 18+	6,895	5,450	-1,445	-21%
All Aged 18-64	1,590	1,640	+50	+3%
All Aged 65+	5,300	3,810	-1,490	-28%
<i>Of Which:</i>				
65+ Community Services	4,685	3,250	-1,435	-31%
65+ Residential Care	560	470	-90	-16%
65+ Nursing Care	315	290	-25	-8%
<i>Source: NASCIS RAP Tables</i>				

<sup>16</sup> Age UK (2017): Health and Care of Older People in England 2017

## Provision of LA Funded Care – Solihull 65+ Population



*Source: NASCIS RAP Tables, ONS Population Estimates*

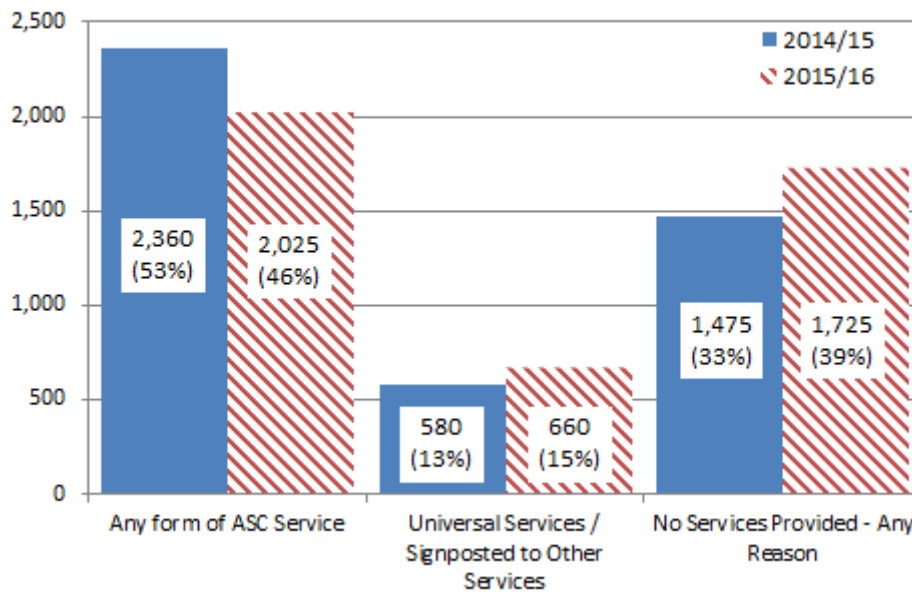
In 2014/15 the way in which social care activity statistics were collected changed and it is not possible to directly compare the new data with statistics collected between 2008/09 and 2013/14. The aim of the new method was to better capture people provided with short-term support (for example after being discharged from hospital) that may not have been discernible previously. However the new data gives no reason to suppose that there has been any significant change in long term trends towards fewer people receiving care.

There were a total of 4,415 new requests for support from people aged 65+ in Solihull in both 2014/15 and 2015/16. In 2014/15 53% of these new requests lead to the provision of some form of short or long-term support, but in 2015/16 this proportion fell to 46% (from 2,360 in 2014/15 to 2,025 in 2015/16). This was consistent with the pattern national trend.

	Outcome of New 65+ Requests	
	2014/15	2015/16
Short Term Support to Maximise Independence	1,040	885
Long Term Support - Nursing Care	40	45
Long Term Support - Residential Care	45	50
Long Term Support - Community	380	305
End of Life	5	0
Ongoing Low Level Support	715	570
Short Term Support (Other)	135	170
Any form of ASC Service	2,360	2,025
Universal Services / Signposted to Other Services	580	660
No Services Provided - Any Reason	1,475	1,725
All New Requests	4,415	4,415
% Receiving an ASC Service	53%	46%

*Source: NASCIS SaLT Tables*

## Outcome of New Requests From Those Aged 65+



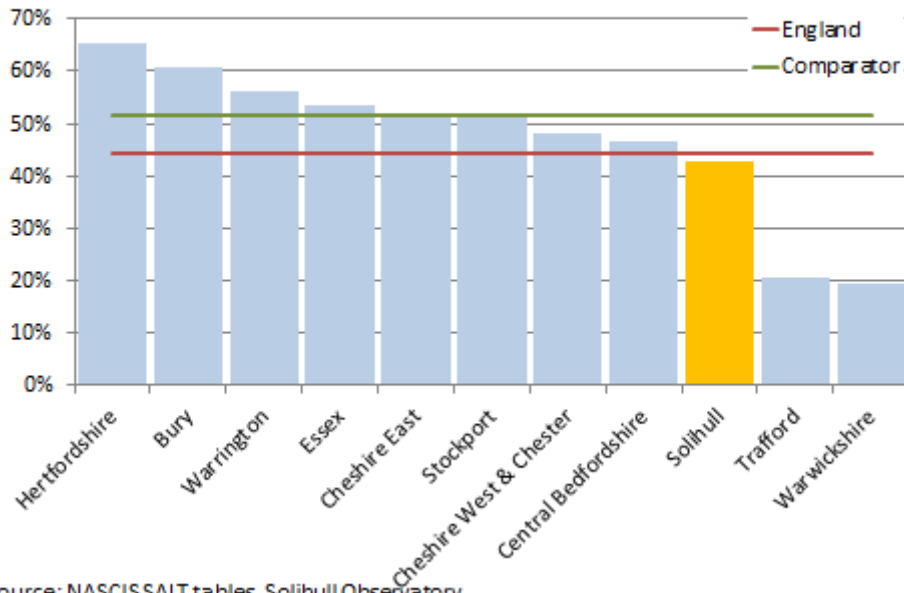
Source: NASCIS SoLT Tables

The number of 65 year olds in Solihull accessing a long-term service (either community or residential/nursing) also fell slightly between 2014/15 and 2015/16 (from 2,400 individuals in 2014/15 to 2,345 in 2015/16).

Age UK analysis suggests that the reductions in LA funded care services described above are a major factor in the increasing size of the carer population and are also contributing to the fact that informal carers are meeting increasingly complex needs. This is shown by the fact that the average number of ADLs and IADLs of people receiving solely informal support increased over the last 15 years or so, rising from an average of 2.9 in 2002/03 to 3.2 in 2014/15.

As well offsetting lower LA funded social care provision, carers also help many of those who receive a funded community based care package to remain in their own home. In 2015/16 43% of Solihull service users in receipt of a community package had identified carer support, in-line with the England average, but below that of the comparator group (52%). The benefits of this informal support are not easily quantifiable, but it is likely that many of Solihull's 1,900 carer supported service users would have require a higher level of funded support were it not for this additional help.

### % ASC Clients Receiving a Community Service at Year End who Have Carer Support

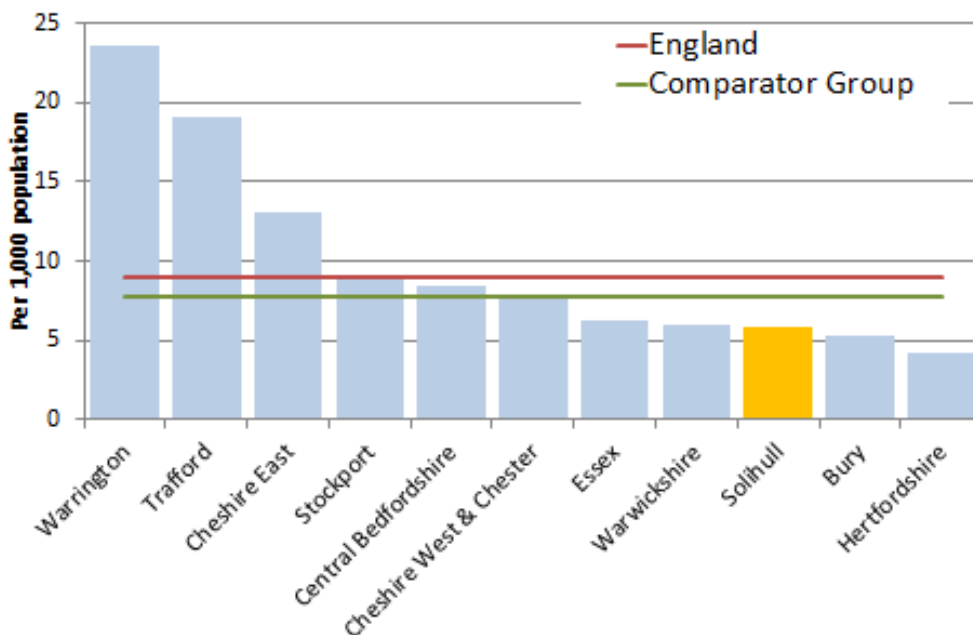


Source: NASCIS SALT tables, Solihull Observatory

### Service Activity

In 2015/16 there were 960 adult carers in contact with Solihull council, equating to 5.79 per 1,000 adults aged 18 and over in the borough. This represents a relatively low level of carer contact when compared with the averages for England (8.79 per 1,000) and Solihull's statistical comparator group (7.81 per 1,000).

### Carers in Contact with Social Services 2015/16



Source: NASCIS SALT tables, Solihull Observatory

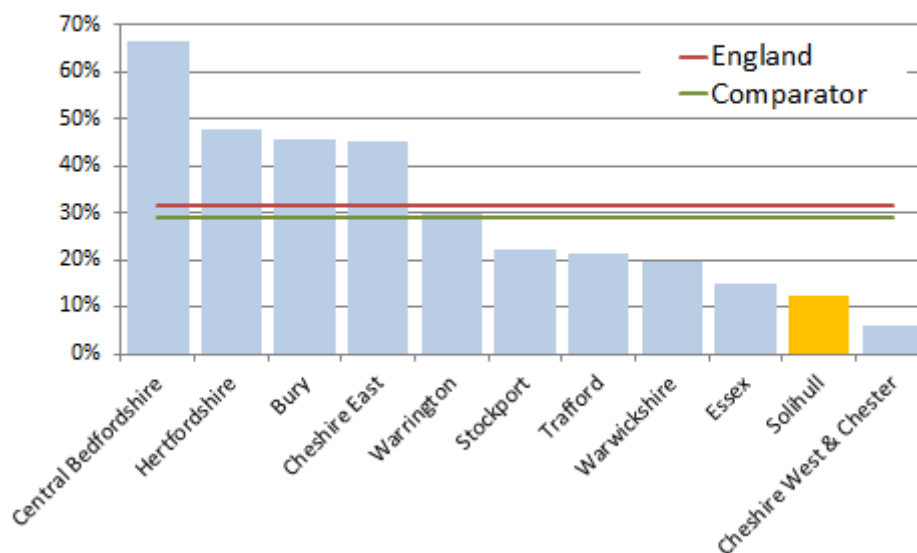
Out of the 960 carers in contact with Solihull social care, 117 received a direct service through a Carers Direct Payment, 679 received information and advice or were signposted to universal services and 160 received no support.

Compared with England and a group of similar comparator Local Authorities a relatively small proportion of Solihull carers in contact with social services in 2015/16 received a direct carers service (13%), although more received information or advice including signposting to universal services (71%). Per head of population the number of Solihull carers receiving a service is substantially below the both the England and comparator averages (0.73 per 1,000 compared to 2.82 and 2.25 per 1,000).

<b>Adult Carers in Contact with Social Services 2015/16</b>						
	% Carer Contacts			Per 1,000 Population		
	Information, Advice/ Signposting	Direct Carer Service	No Support	Information, Advice / Signposting	Direct Carer Service	Either Info & Advice or Direct Service
Solihull	71%	13%	17%	4.12	0.73	4.85
England	50%	31%	19%	4.47	2.82	7.29
Comparator	56%	29%	16%	4.34	2.25	6.59

*Source: NASICS SALT Tables, Solihull Observatory*

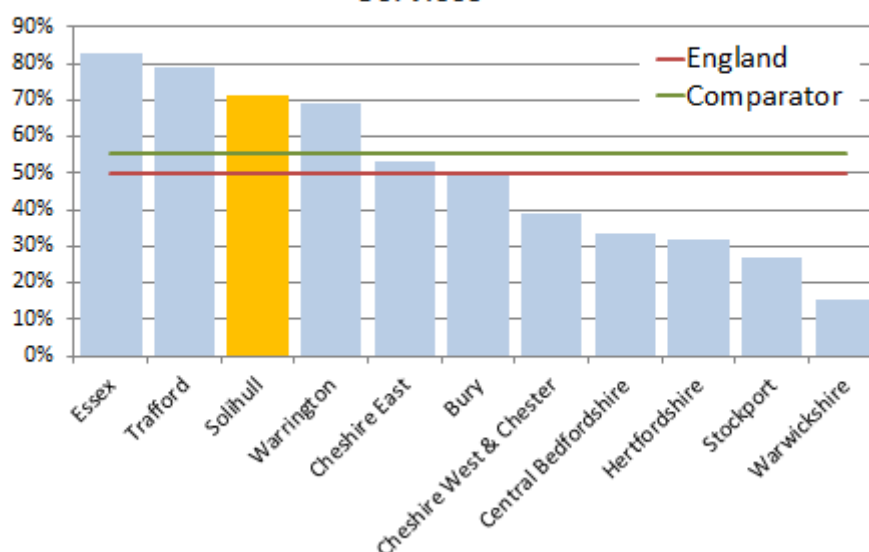
### % of Carers in Contact with Social Services Receiving a Direct Carers Service



Source: NASICS SALT tables, Solihull Observatory



### % of Carers in Contact with Social Services Provided Information & Advice or Signposted to Universal Services



Source: NASCIS SALT tables, Solihull Observatory

The table below shows the number of carer contacts in Solihull in 2015/16 by age of carer. Carers aged 65+ accounted for 44% of all carer contacts in 2015/16, but only 29% of direct carer services.

Age of Carer	Number of Carers 2015/16			
	Receiving a Direct Service	Information and advice	No Service Provided	Total Carer Contacts
Under 18	0	1	0	1
18-64	83	360	85	528
65-84	30	248	55	333
85 and over	4	70	20	94
<b>Total</b>	<b>117</b>	<b>679</b>	<b>160</b>	<b>960</b>
<b>% 65+</b>	<b>29%</b>	<b>47%</b>	<b>47%</b>	<b>44%</b>

Source: SMBC

As the table below shows the number of carers receiving either a direct service or information & advice fell by -20% (-199 individuals) in 2015/16.

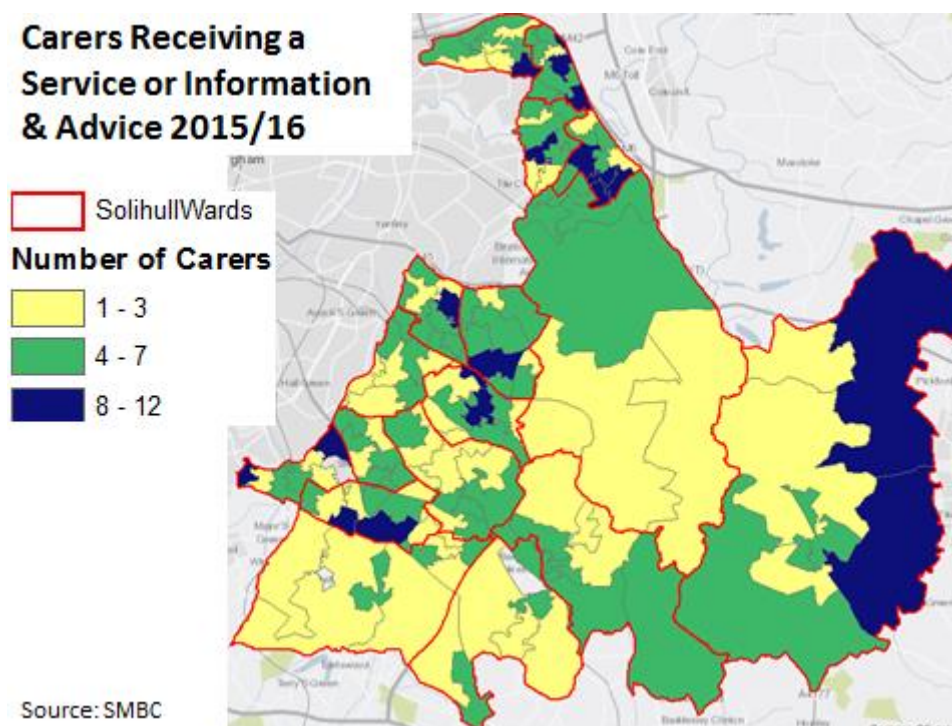
Age of Carer	Carers Receiving a Direct Service or Information & Advice				Change 2014/15 – 2015/16	
	2012/13	2013/14	2014/15	2015/16	Number	%
18-64	489	428	512	464	-48	-9%
65+	514	429	503	352	-151	-30%
<b>Total</b>	<b>1,003</b>	<b>857</b>	<b>1,015</b>	<b>816</b>	<b>-199</b>	<b>-20%</b>

Source: SMBC

35% of Carers receiving a direct carers service in 2015/16 live in the three North Solihull Regeneration wards (Chelmsley Wood, Kingshurst & Fordbidge, Smith's Wood), although the proportion of those receiving information and advice only who live in this area is much lower (22%).

	Number of Carers 2015/16		
	Information & Advice	Receiving a Direct Service	Total
North Solihull	108	38	146
Rest of Borough	387	72	459
% Living in North Solihull	22%	35%	24%
<i>Source: SMBC</i>			

As the map below shows the distribution of carers receiving either a direct carers service or information and advice in 2015/16 LSOA Map was relatively uniform across the borough, albeit it with some clusters in North Solihull, Shirley and Meriden.

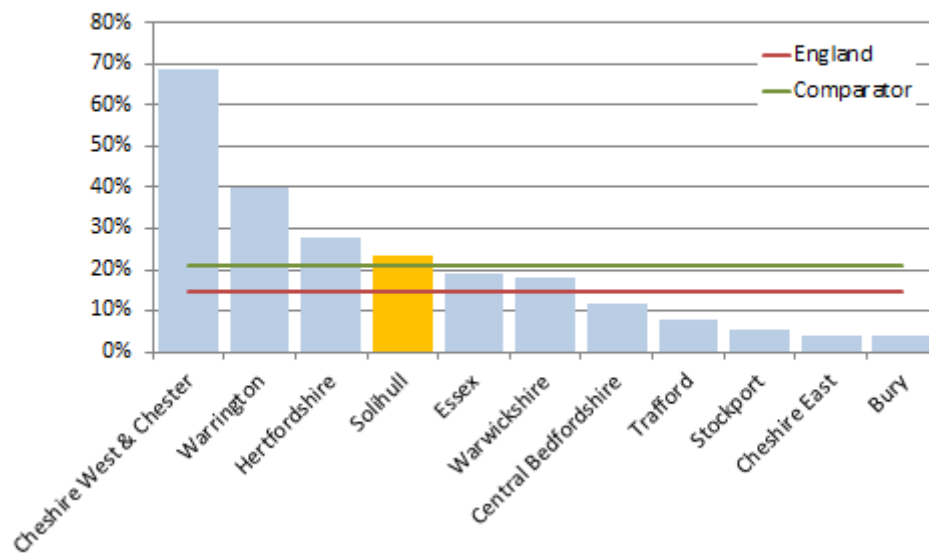


In addition to those carers receiving a direct service others benefit from support provided directly to the cared for person, principally through respite care. In 2015/16 220 Solihull carers received this type of service via the person the care for. This equates to 24% of all carers in contact with services, above both the England (15%) and comparator group averages (21%). Although it should be noted as when expressed on a per head of population basis, Solihull's provision of respite services is slightly below the comparator average.

Respite Provision 2015/16				
	All Carer Contacts	Respite Provision	% Carers Benefiting from Respite	Respite Provision per 1,000 Population
Solihull	955	225	24%	1.36
England	386,600	57,440	15%	1.33
Comparator	32,375	6,840	21%	1.65

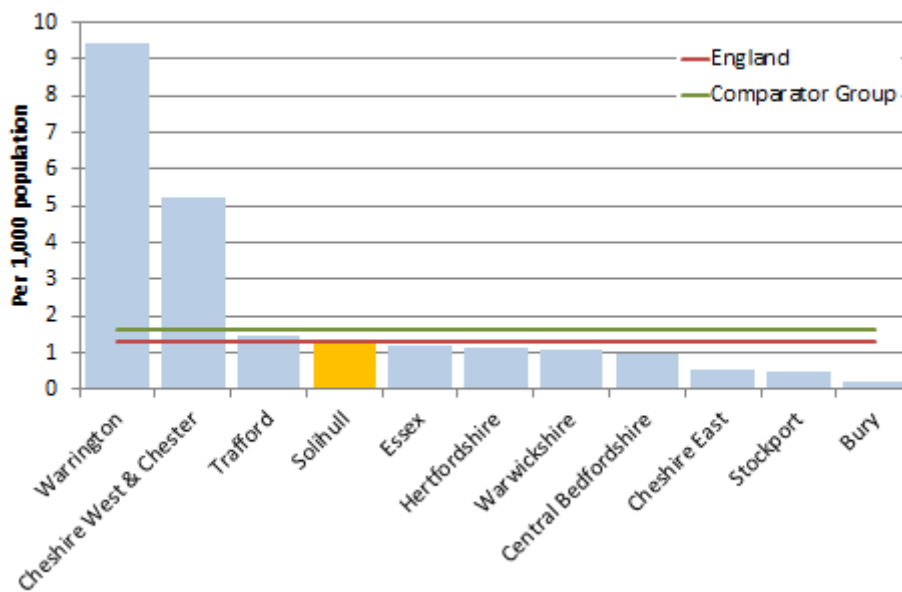
Source: NASICS SALT Tables, Solihull Observatory

### % of Carers in Contact with Social Services Receiving Respite Services via the Person They Care For



Source: NASICS SALT tables, Solihull Observatory

### Respite Provision per 1,000 Population 2015/16



Source: NASICS SALT tables, Solihull Observatory

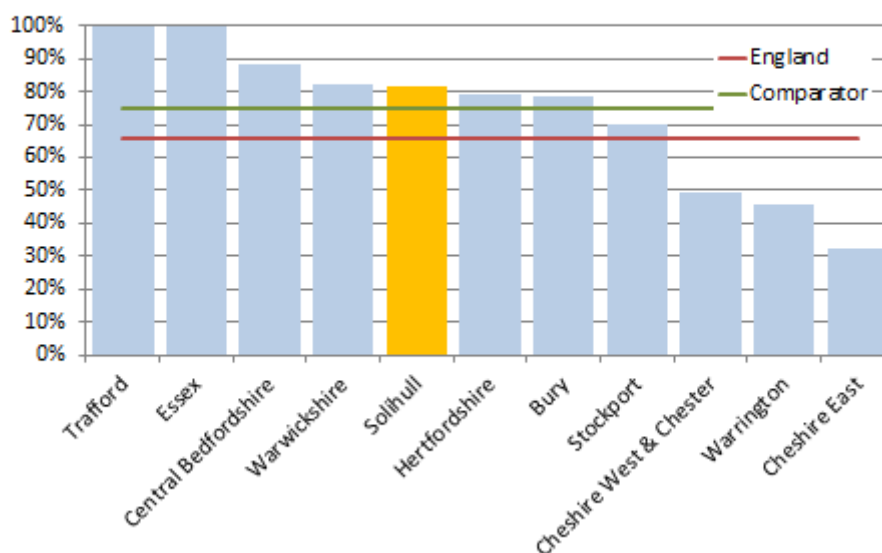
The number of people a respite service in Solihull increased by 18% in 2015/16 compared with the previous financial year (from 180 to 220 individuals). This increase in provision is higher than that recorded across England as a whole (+5%).

A broader consideration of support and services received by carers, including survey evidence from Carers UK is included under the heading practical support and access to services in section 5 of this report (The Caring Experience).

The Adult Social Care function of Solihull 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.

In 2015/16 782 Solihull of the 960 carers in contact with social services were subject to a review or assessment by Solihull Adult Social Care services. This means that 81% of Solihull carers in contact with social services received a review compared with the England average of 66% and the comparator average of 75%.

### % of Carers in Contact with Social Services Receiving a Review/Assessment in 2015/16



Source: NASCIS SALT tables, Solihull Observatory

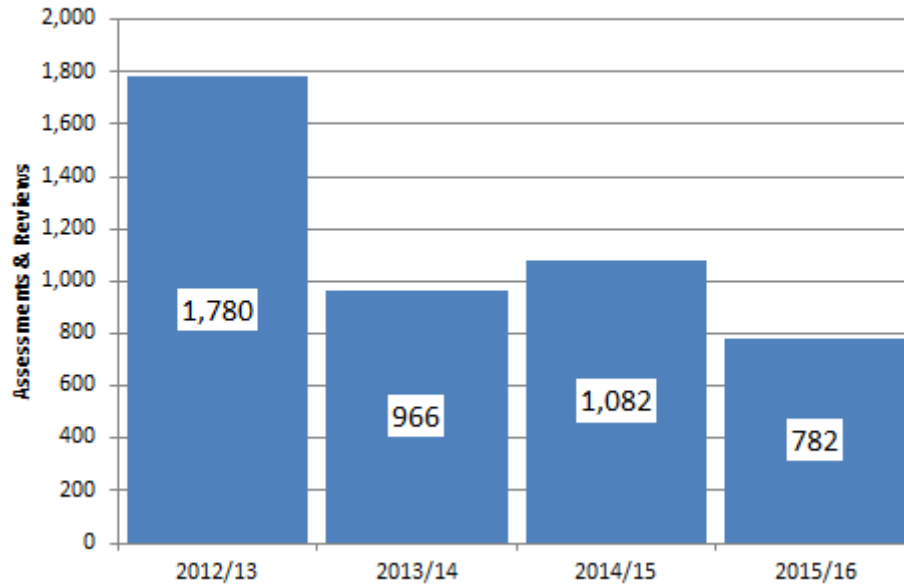
Of these 78% (609) were conducted with the carer alone and 32% (173) were undertaken jointly with the cared for person. Those aged 18-64 accounted for 56% (435) of carer reviews and assessments in 2015/16 and those aged 65+ 44% (348).

Age group of Carer	Carer Assessments and Reviews 2015/16		
	Single	Joint	Total
Under 18		1	1
18-64	359	74	433
65-84	204	70	274
85 and over	46	28	74
<b>Total</b>	<b>609</b>	<b>173</b>	<b>782</b>

Source: SMBC

There were 300 fewer carer assessments/ reviews in Solihull in 2015/16 than in the previous year (-28%).

## Carers Receiving an Assessment or Review



Source: SMBC

## Performance and Benchmarking

Solihull's performance in relation to carers and carer services can be measured through the Adult Social Care Outcomes Framework (ASCOF), the Department of Health's main tool for setting direction and strengthening transparency in adult social care. The ASCOF provides a comprehensive overview of the outcomes achieved by people who use health and care services through a range of measures grouped under four domains:

- Domain 1: Enhancing quality of life for people with care and support needs;
- Domain 2: Delaying and reducing the need for care and support;
- Domain 3: Ensuring that people have a positive experience of care and support;
- Domain 4: Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm.

The table below shows the six ASCOF measures that relate directly to carers and carer services. It is also worth monitoring three other measures relating to service user activity that are likely to be influenced by the role of carers in helping service users to maintain their independence.

ASCOF Performance Measures		
Direct Carers Measures		
Domain	Measure	Date
Domain 1: Enhancing quality of life for people with care	1C part 2B - The proportion of carers who receive direct payments	2015/16

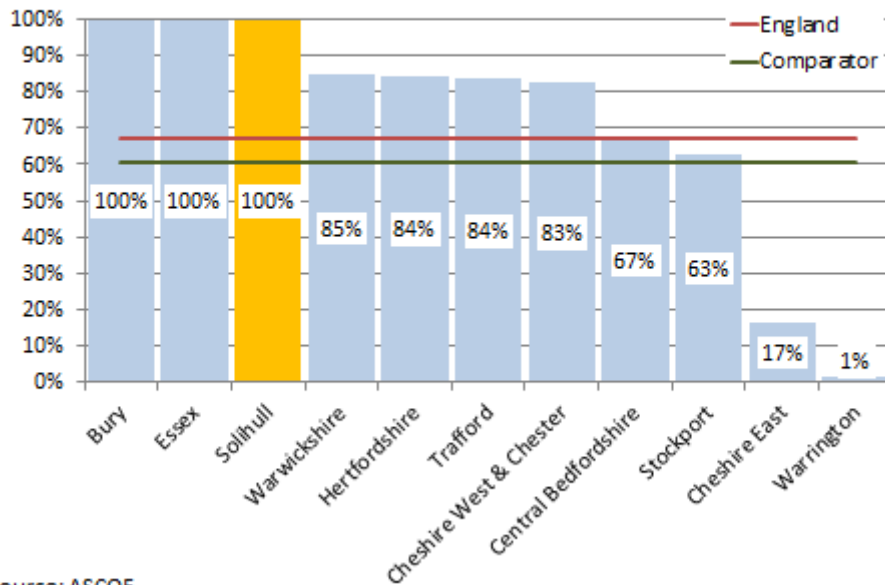
and support needs	1D - Carer-reported quality of life score	2014/15
	1I part 2 - The proportion of carers who reported that they had as much social contact as they like	2014/15
Domain 3: Ensuring that people have a positive experience of care and support	3B - Overall satisfaction of carers with social services	2014/15
	3C - The proportion of carers who report that they have been included or consulted in discussion about the person they care for	2014/15
	3D part 2 - The proportion of carers who find it easy to find information about support	2014/15
<b>Indirect Measures</b>		
<b>Domain</b>	<b>Measure</b>	<b>Date</b>
Domain 2: Delaying and reducing the need for care and support	2A part 1- Long-term support needs of younger adults (aged 18-64) met by admission to residential and nursing care homes	2015/16
	2A part 2 - Long-term support needs of older adults (aged 65 and over) met by admission to residential and nursing care homes	2015/16
	2C part 2 - Delayed transfers of care from hospital which are attributable to adult social care	2015/16

### **1C part 2B - The proportion of carers who receive direct payments**

Rationale: Research has indicated that personal budgets impact positively on well-being, increasing choice and control, reducing cost implications and improving outcomes. Studies have shown that direct payments increase satisfaction with services and are the purest form of personalisation. The Care Act places personal budgets on a statutory footing as part of the care and support plan.

In 2015/16 100% of Solihull carers receiving a service were in receipt of a personal budget compared to the England average of 67.4% and the statistical neighbour group average of 60.4%.

## The proportion of carers who receive direct payments 2015/16



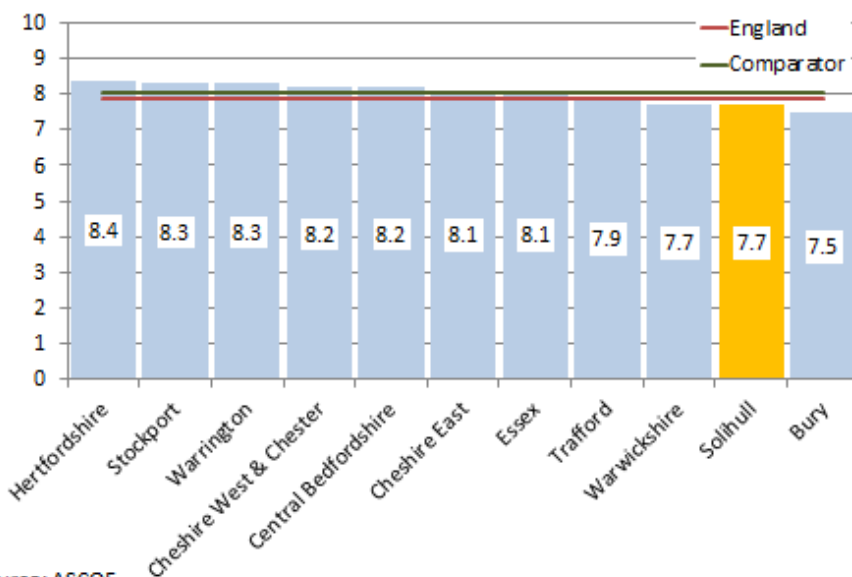
Source: ASCOF

### 1D - Carer-reported quality of life score

Rationale: This measure gives an overarching view of the quality of life of carers based on outcomes identified through research by the Personal Social Services Research Unit. This is the only current measure related to quality of life for carers available, and supports a number of the most important outcomes identified by carers themselves to which adult social care contributes.

In 2014/15 Solihull's outcome score for this measure was, at 7.7 below both the England (7.9) and comparator average (8.0).

## Carer-reported quality of life Score 2014/15



Source: ASCOF



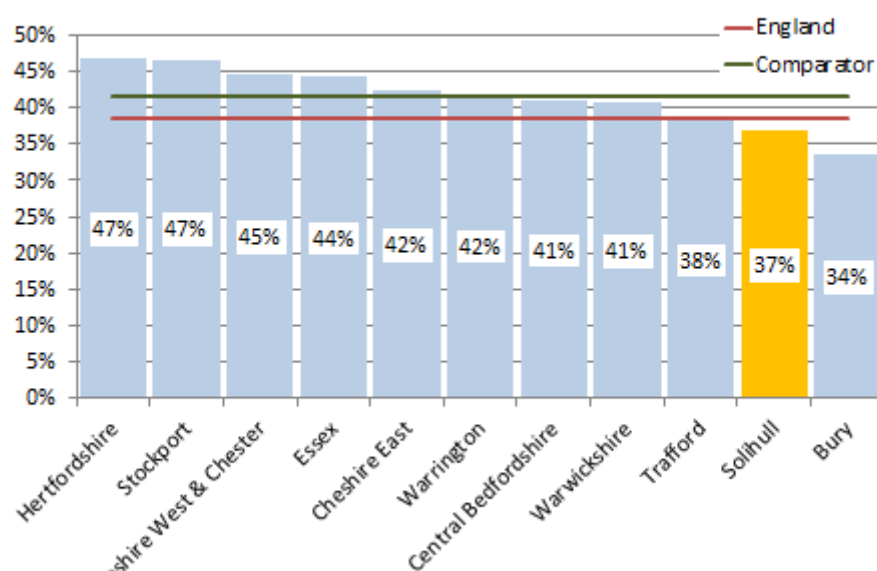
## 1I part 2 - The proportion of carers who reported that they had as much social contact as they like

Rationale: There is a clear link between loneliness and poor mental and physical health. A key element of the Government's vision for social care is to tackle loneliness and social isolation, supporting people to remain connected to their communities and to develop and maintain connections to their friends and family. This measure draws on self-reported levels of social contact as an indicator of social isolation among carers.

In 2014/15 36.8% of Solihull carers said that they have as much social contact as they like below both the England (38.5%) and comparator averages (41.5%).

Preliminary results for Solihull only are now available from the 2016/17 Carers Survey and are covered in section 5 of this report (The Caring Experience).

The proportion of carers who reported that they had as much social contact as they like 2014/15



Source: ASCOF

## 3B - Overall satisfaction of carers with social services

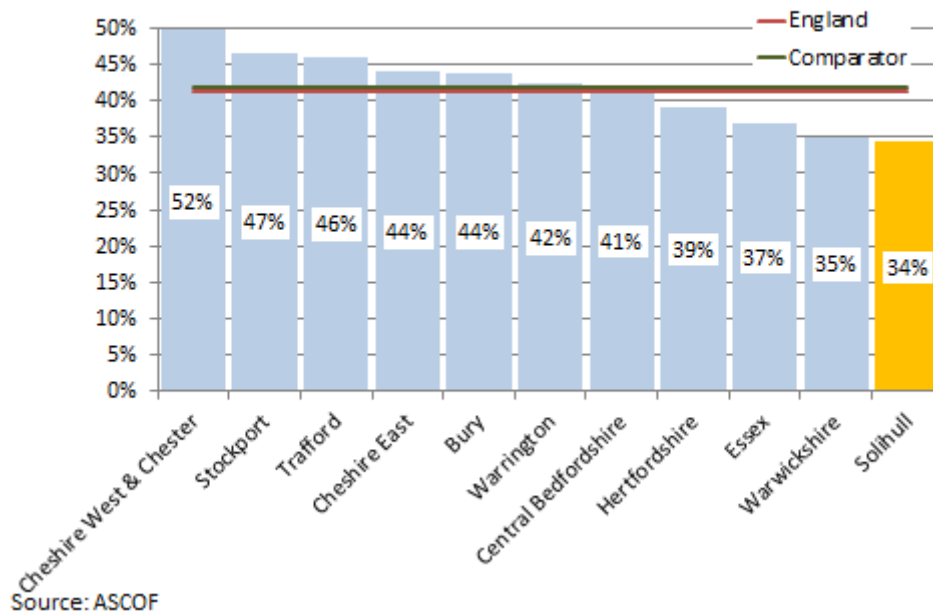
Rationale: This measures the satisfaction with services of carers of people using adult social care, which is directly linked to a positive experience of care and support. Analysis of user surveys suggests that reported satisfaction with services is a good predictor of the overall experience of services and quality.

In 2014/15 34.3% of Solihull carers reported that they were satisfied with social services, below both the England (41.2%) and comparator (42%) averages.

Preliminary results for Solihull only are now available from the 2016/17 Carers Survey and are covered in section 4 of this report (What Carers Are Telling Us).



## Overall satisfaction of carers with social services 2014/15



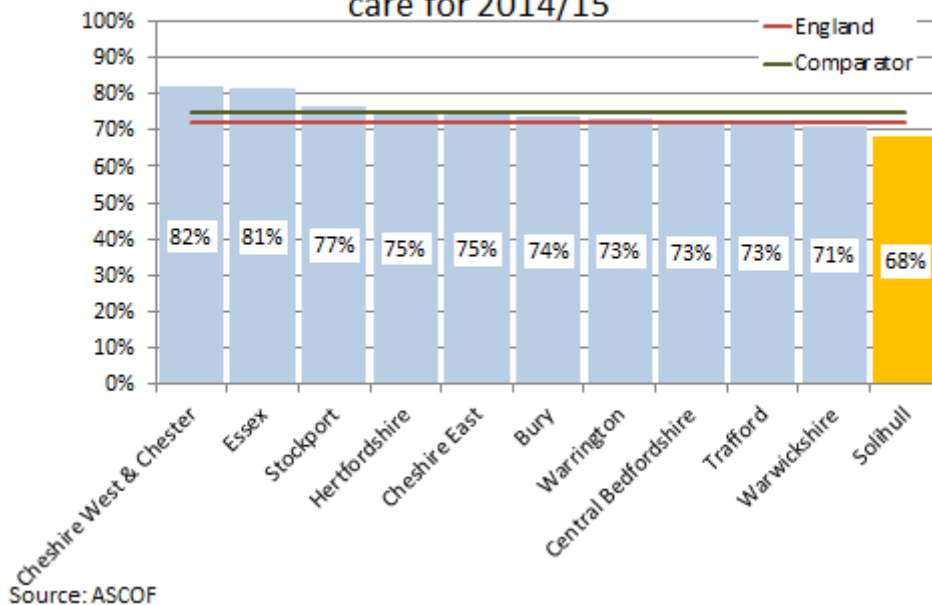
### 3C - The proportion of carers who report that they have been included or consulted in discussion about the person they care for

Rationale: Carers should be respected as equal partners in service design for those individuals for whom they care – this improves outcomes both for the cared for person and the carer, reducing the chance of breakdown in care. This measure reflects the experience of carers in how they have been consulted by both the NHS and social care.

In 2014/15 68.3% of Solihull carers reported that they were included or consulted in discussion about the person they care for below both the England (72.3%) and comparator (74.8%) averages.

Preliminary results for Solihull only are now available from the 2016/17 Carers Survey and are covered in section 4 of this report (What Carers Are Telling Us).

The proportion of carers who report that they have been included or consulted in discussion about the person they care for 2014/15



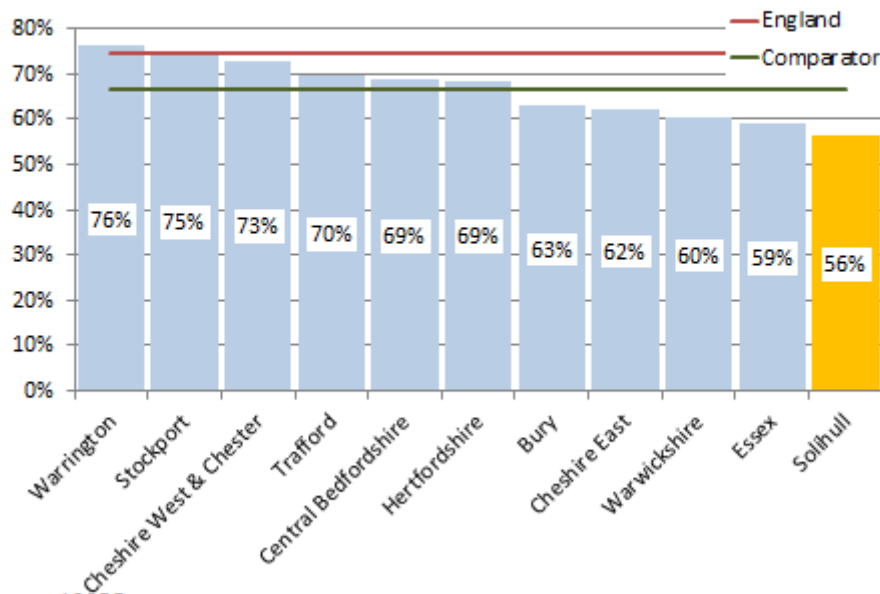
**3D part 2 - The proportion of carers who find it easy to find information about support**

Rationale: Information is a core universal service and a key factor in early intervention and reducing dependency. Improved and/or more information benefits carers and the people they support by helping them to have greater choice and control over their lives. This may help to sustain caring relationships through, for example, reduction in stress, improved welfare and physical health improvements.

In 2014/15 56.4% of Solihull carers reported that it was easy to find information about support, below both the England (74.6%) and comparator (66.4%) averages.

Preliminary results for Solihull only are now available from the 2016/17 Carers Survey and are covered in section 4 of this report (What Carers Are Telling Us).

## The proportion of carers who find it easy to find information about 2014/15



Source: ASCOF

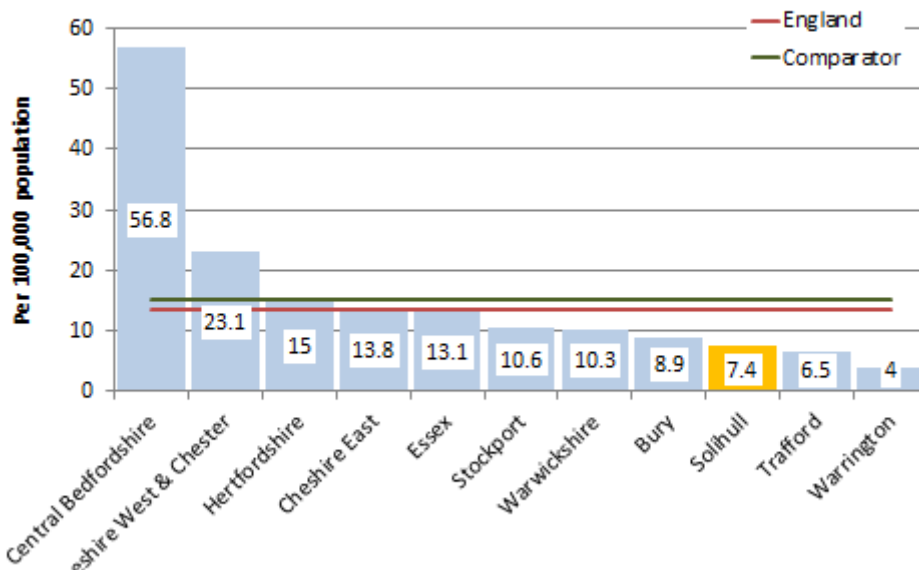
### 2A part 1- Long-term support needs of younger adults (aged 18-64) met by admission to residential and nursing care homes

Rationale: Avoiding permanent placements in residential and nursing care homes is a good measure of delaying dependency, and the inclusion of this measure in the framework supports local health and social care services to work together to reduce avoidable admissions. Research suggests that, where possible, people prefer to stay in their own home rather than move into residential care. However, it is acknowledged that for some client groups that admission to residential or nursing care homes can represent an improvement in their situation.

It is included in this section because in some cases a permanent admission to a nursing or residential home may be the consequence of a carer no longer being able to fulfil their caring role.

In 2015/16 there were just 9 permanent admissions of adults aged 18-64 in Solihull, equating to 7.4 per 100,000. This represents good performance relative to the England 13.3 per 100,000 and comparator (15.1 per 100,000) averages.

## Permanent Admissions to Nursing or Residential Care Among Adults Aged 18-64 2015/16



Source: ASCOF

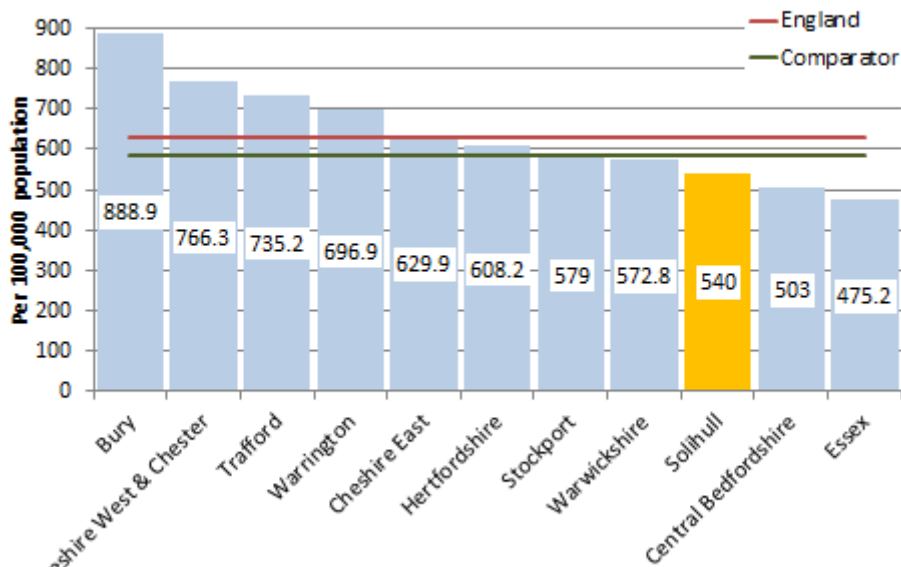
### 2A part 2- Long-term support needs of older adults (aged 65 and over) met by admission to residential and nursing care homes

Rationale: Avoiding permanent placements in residential and nursing care homes is a good measure of delaying dependency, and the inclusion of this measure in the framework supports local health and social care services to work together to reduce avoidable admissions. Research suggests that, where possible, people prefer to stay in their own home rather than move into residential care. However, it is acknowledged that for some client groups that admission to residential or nursing care homes can represent an improvement in their situation.

It is included in this section because in some cases a permanent admission to a nursing or residential home may be the consequence of a carer no longer being able to fulfil their caring role.

In 2015/16 there were 237 permanent admissions of adults aged 65+ in Solihull, equating to 540 per 100,000. This represents good performance relative to the England 628 (per 100,000) and comparator (586 per 100,000) averages.

## Permanent Admissions to Nursing or Residential Care Among Adults Aged 65+ 2015/16



Source: ASCOF

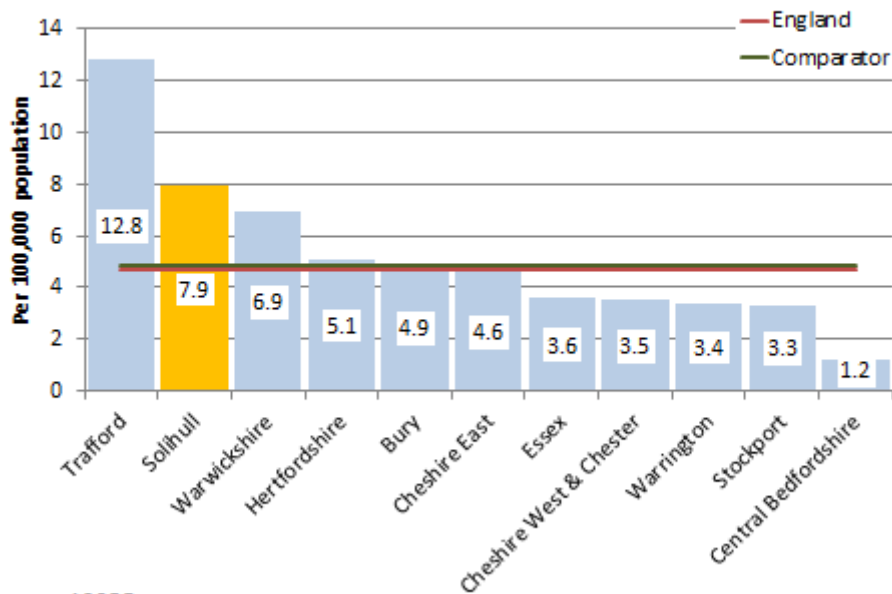
### 2C part 2 - Delayed transfers of care from hospital which are attributable to adult social care

Rationale: This measures the impact of hospital services (acute, mental health and non-acute) and community-based care in facilitating timely and appropriate transfer from all hospitals for all adults. This indicates the ability of the whole system to ensure appropriate transfer from hospital for the entire adult population. It is an important marker of the effective joint working of local partners, and is a measure of the effectiveness of the interface between health and social care services. Minimising delayed transfers of care and enabling people to live independently at home is one of the desired outcomes of social care.

It is included in this section because in some cases a delayed transfer may be the consequence of a carer not being able to provide the necessary care for the person leaving hospital.

In 2015/16 there were just 13 delayed transfers attributable to social care in Solihull, equating to 7.9 per 100,000. However, this represents below average performance relative to England (4.7 per 100,000) and the comparator group of statistical neighbours (4.8 per 100,000).

## Delayed Transfers of Care Attributable to Social Care 2015/16



Source: ASCOF

### Financial Investment in Carers

In 2014/15, the Council invested resources of £859,422 to support carers, with £350,000 additional funding coming from the CCG via a S256 grant which provided total funding of £1,209,422 for investment in Carers.

The figures for 2015/16 and 2016/17, including Information & Advice are shown in the table below.

Funding Source	Investment in Carers in Financial Year			Change 2014/15 – 2016/17
	2014/15	2015/16	2016/17	
SMBC Invested	£859,422	£781,640	£682,730	-176,692 (-15%)
CCG Invested	£350,000	£350,000	£350,000	£0 (0%)
<b>Total</b>	<b>£1,209,422</b>	<b>£1,131,640</b>	<b>£1,032,730</b>	<b>-176,692 (-15%)</b>

Source: SMBC Adult Care & Support Finance

On this basis financial investment in carers is set to fall by 6% between 2014/15 and 2015/16 and a further 9% in 2016/17. In total this is a 15% reduction in investment over two years amounting to -£176,692.

## Section 4: What Solihull Carers Are Telling Us

### Adult Carers

#### Satisfaction with Services

Every two years Solihull MBC carries out a Carers Survey on behalf of the Department of Health. The survey is a statutory requirement for the Council, although participation by clients is on a voluntary basis. The sample consists of carers aged 18 and over who are caring for someone aged 18 or over.

The survey is designed to capture carers' thoughts, opinions and feelings on a number of topics thought to be integral to helping them achieve a balanced life alongside their caring role. Specifically the survey seeks to:

- Assess whether services received by carers are helping them in their caring role and their life outside of caring;
- Assess carers' perception of services provided to the cared for person.

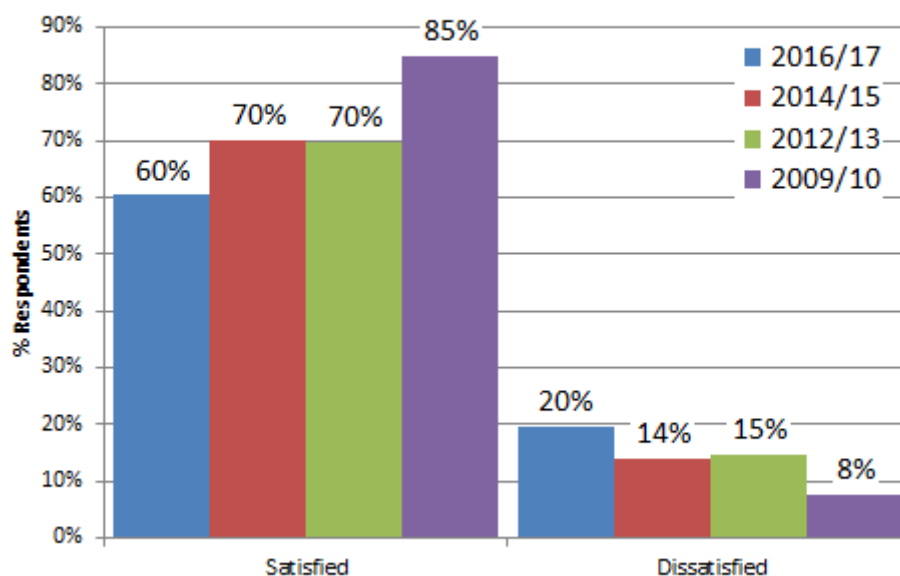
At the time of writing national benchmarking data has not been released for 2016/17, although Solihull's performance relative to England and a group of comparator Local Authorities is covered for earlier years under the heading of performance in Section 3 of this report (Services for Solihull Carers).

In 2016/17 60% of Solihull respondents to the Carers Survey who had received a service in the last 12 months said that they were satisfied with the service (32% extremely or very satisfied, 28% quite satisfied) compared with 20% who were dissatisfied (12% quite dissatisfied, 8% very or extremely dissatisfied). This marks a reduction in satisfaction compared with 2014/15 (70% satisfied, 14% dissatisfied) and is markedly less positive than the results from 2009/10 (85% satisfied, 8% dissatisfied).

Satisfaction with Services	Count	% of those receiving service			
		2016/17	2014/15	2012/13	2009/10
Extremely satisfied	25	11%	13%	14%	20%
Very satisfied	48	21%	22%	24%	38%
Quite satisfied	63	28%	36%	32%	26%
Neither satisfied nor dissatisfied	45	20%	16%	16%	8%
Quite dissatisfied	27	12%	8%	9%	5%
Very dissatisfied	12	5%	2%	3%	1%
Extremely dissatisfied	5	2%	3%	3%	1%

*Source: Carers Survey 2009/10 to 2016/17*

## Overall Satisfaction with Support or Services



Source: SMBC Carers Survey

It is also worth noting that service users are much more positive than carers, with 93% of Solihull respondents to the 2015/16 service user survey saying that they were satisfied with the care and support services they received compared with just 60% of carers.

A range of research evidence<sup>17</sup> highlight the importance that carers place on being involved in the care provided to the person they care for.

In 2016/17 66% of Solihull respondents aware of discussions taking place about the person they care for feel that they have been sufficiently involved or consulted (33% always and 33% usually) compared with 34% who have not been consulted enough (24% sometimes, 10% never).

Involved & Consulted in Care for Cared for Person	Count	% of those who are aware about discussions			
		2016/17	2014/15	2012/13	2009/10
Always felt involved or consulted	65	33%	36%	37%	47%
Usually felt involved or consulted	65	33%	32%	31%	29%
Sometimes felt involved or consulted	48	24%	24%	26%	18%
Never felt involved or consulted	20	10%	8%	7%	6%

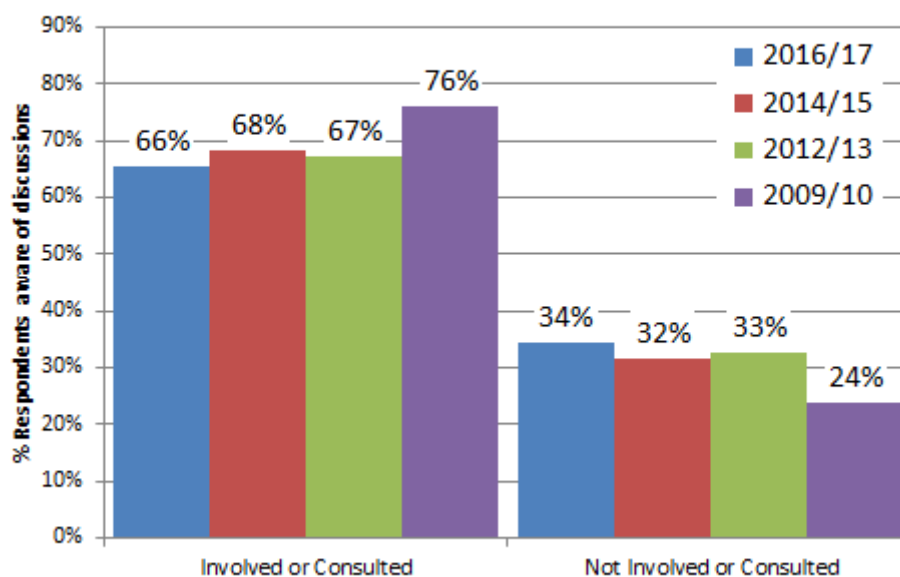
Source: Carers Survey 2009/10 to 2016/17

The results for 2016/17 are broadly in-line with the previous two surveys, but are less positive than those from 2009/10.

<sup>17</sup> The Princess Royal Trust for Carers: Putting People First Without Putting People Second



### Extent to Which Carers Feel Involved or Consulted in Discussions About the Support or Services Provided to the Cared for Person



Source: SMBC Carers Survey

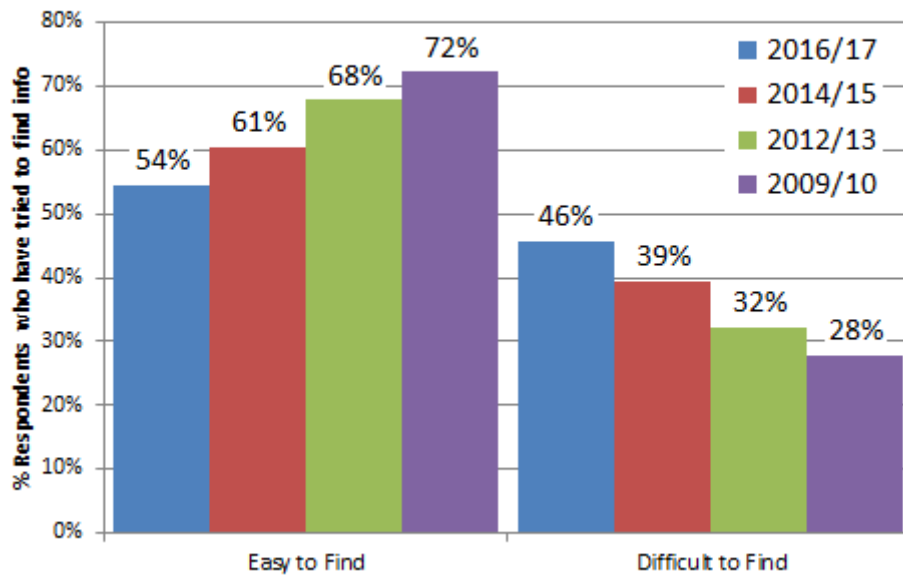
Carers also regard access to information and advice as highly important in their caring role and an important component of their overall service package. 54% of Solihull respondents to the 2016/17 who tried to find information about support services or benefits said that they found it easy to find (6% very easy and 48% fairly easy) compared with 46% who found it difficult to find (29% fairly difficult, 17% very difficult).

Ease of Finding Information or Advice	Count	% of those who have tried to find information			
		2016/17	2014/15	2012/13	2009/10
Very easy to find	13	6%	15%	16%	23%
Fairly easy to find	98	48%	45%	52%	49%
Fairly difficult to find	59	29%	26%	23%	22%
Very difficult to find	34	17%	14%	9%	6%

Source: Carers Survey 2009/10 to 2016/17

The proportion of carers who say that it has is easy to find information has fallen in each of the last three surveys and is considerably lower than that recorded in 2009/10 (54% compared to 72%).

## Finding Information and Advice About Support, Services or Benefits



Source: SMBC Carers Survey

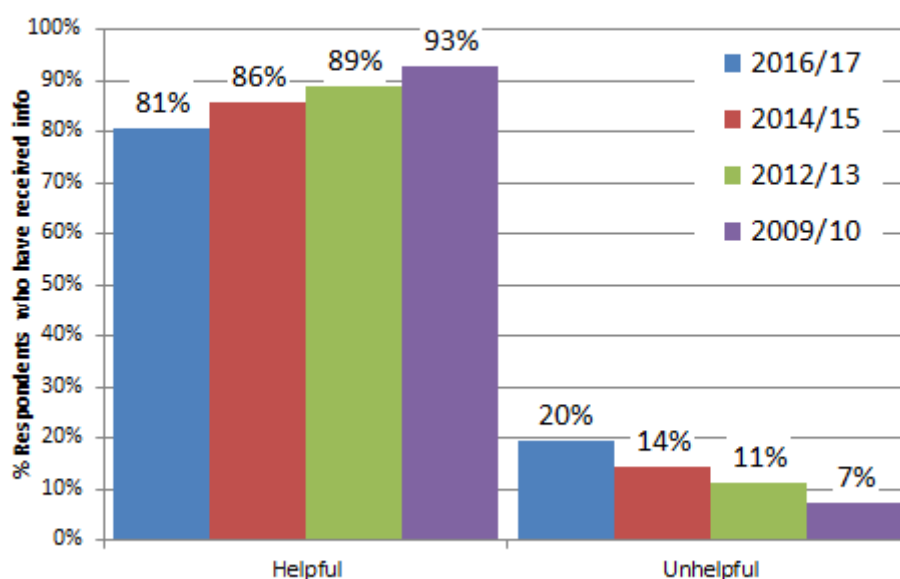
81% of respondents in Solihull who have received advice or information in the last 12 months said that they found it helpful (24% very helpful and 57% fairly helpful) compared with 20% who found it unhelpful (15% fairly unhelpful, 5% very unhelpful).

Ease of Finding Information or Advice	Count	% of those who have received information			
		2016/17	2014/15	2012/13	2009/10
Very helpful	48	24%	31%	29%	43%
Quite helpful	113	57%	55%	60%	49%
Quite unhelpful	30	15%	10%	10%	6%
Very unhelpful	9	5%	4%	2%	2%

Source: Carers Survey 2009/10 to 2016/17

The proportion who have found the information they have received helpful has fallen in each of the last three surveys and is now significantly lower than in 2009/10 (81% compared to 93%).

## Extent to Which Information and Advice About Support, Services or Benefits Has Been Helpful



Source: SMBC Carers Survey

### Consultation Feedback

Experts by Experience, who are carers themselves, helped to run a number of consultation events in 2014. In many ways the feedback from the nearly 300 participating carers of differing ages and caring for loved ones with diverse and sometimes complex conditions, echo the findings of the best practice guidelines and research outlined in section six of this report (What Works). The key messages from the consultation are summarised below:

**Recognition and respect:** Some carers said that they did not feel fully recognised and respected as the carer and therefore were not always involved in the design of the care package for the person they cared for, and they sometimes needed time to ‘take it in’ and work out how it fitted. They want to be consulted with and involved in the decision making and care planning process for the person being cared for in a person centred way. A good relationship with professionals and building understanding of carers’ circumstances was highly valued. Some carers expressed concern that adult social care processes required them to ‘start again’ when they made contact rather than go back to social workers they had got to know.

Some carers acknowledged that they did not recognise themselves as carers and that it would be helpful if other services especially GP’s, hospitals and Social Care helped in this. It would also help if there was more flexibility with appointments especially for people with dementia or autism or others who struggle with long waits. Some carers said “It would be helpful if there was a scheme like the Disabled blue badge scheme for carers to be able to park more easily especially when their time is short”, for example to be able to do every day errands or because of the condition of the cared for it makes it difficult to complete things in the short parking times.

It was also highlighted that while carers may need training to support them in their caring role that professionals and others needed training to help them understand the needs of

carers and the challenges faced by them. Carers' assessments should be promoted positively and be triggered at information and/or treatment or diagnosis points. There is also some fear for carers that they will be found lacking and the person they care for will be taken away from them and placed in residential care and for the parents of young carers and child carers that they will be found to be lacking as parents and have their child removed. Carers want to feel confident in the services that are available to help and support them. Carers want to be listened to and supported to have their say.

**Advice and information:** Good quality advice and information is important to carers in a range of formats, it needs to be concise, up to date and jargon free. The content available needs to be wide ranging, information and explanations of what help is available including for example financial, direct payments and benefits, health, conditions, and carers assessments. Information on the internet should be improved and expanded locally. There are still many older people not accessing the web but also young carers who wanted alternatives such as information sheets. Newsletters produced by the Carers Centre were valued by carers of all ages. They can be picked up, put down, and kept. They are important in making carers feel part of a network and news and events was felt to be as important as service information. Many carers felt that a 'one stop shop' where you could get basic information would be helpful and then you could be put in touch with more specialist agencies.

Information of different kinds will be needed by carers at different points/events in their lives, e.g. diagnosis, hospital discharge, thinking of giving up work. Carers will often need advice and help when their caring role comes to an end. Training to help them in their caring role such as first aid and moving and lifting but also cooking, budgeting and healthy lifestyle choices. Those carers who belonged to carers groups such as the ones run by the Carers Centre and Alzheimer's Society found them useful not only by providing information but also emotional support and friendship.

**Respite breaks:** Carers need to have a life of their own, alongside their caring role. Carers of all ages agreed that they needed a break, a respite from caring and that this varied according to their own individual circumstances. That breaks need to be flexible from a few hours to several days, not just in the daytime but in the evening, giving carers greater opportunities to be involved in family and community events. Some carers wanted the respite to take place in their own homes when it was for a longer period of time such as overnight or for a few days as this was often less stressful for the cared for to be in their own familiar surroundings. Carers and those they care for sometimes wanted a break together which was supported and so took some of the stresses and strains off the carer. Carers emphasised the need for day care for their cared for in particular those with dementia. Younger carers wanted more opportunities to do things together and to go away with each other on residential events for example the young carers' festival. Carers also identified the need for an emergency respite care service so that they would have peace of mind should the unexpected happen.

**Carers' health and wellbeing:** A number of carers referred to the pressures of long term caring and that services, usually health and social care, should recognise this and not just respond to immediate needs. Caring roles which involve daily personal and physical care have a significant impact on the carers' physical and emotional health and that there should be health checks for carers and counselling available.

There is also a sense of loss for what might have been in terms of family life, career and future life depending on the circumstances of caring. Carers need to be supported to stay mentally and physically well and to be treated with dignity and respect.

## Young Carers

### **Solihull Young Carers Survey**

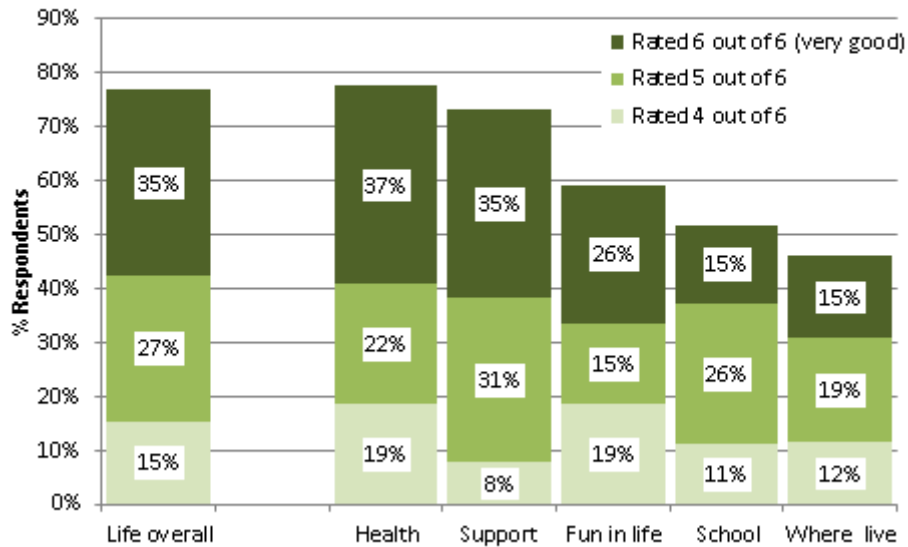
A 2013 survey of 30 Young Carers ranging from 5 to 18 years in contact with the Solihull Young Carers Centre identified a number of the same issues outlined in the national research discussed in section 5. Specifically the Solihull Carers Centre survey found that:

- 69% had been bullied at school, although none definitely stated that the cause was the fact that they were a carer.
- 77% of respondents ranked their life overall as positive, with 35% placing themselves at the top of a ranking scale of one (very bad) to six (very good). Young carers were particularly positive about their own health and the amount of support and help from family and friends. Fewer positive responses were evident in terms of the area where the young person lives in Solihull, their school and the amount of fun in their life.

<b>Quality of Life Measures Ranked on Scale of 1 (Very bad) to 6 (Very Good)</b>						
	<b>Number of Negative Responses</b>			<b>Number of Positive Responses</b>		
	<b>1 (very bad)</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6 (very good)</b>
Life overall	2	2	2	4	7	9
Your health	2	2	2	5	6	10
Support family/friends	3	3	1	2	8	9
Fun in life	3	2	6	5	4	7
Your school	4	3	6	3	7	4
Where you live	4	2	8	3	5	4

*Source: Solihull Young Carers Survey 2013*

## Solihull Young Carers Survey 2013: Positive Responses to Quality of Life Measures



- A large majority (85%) of the young people surveyed admitted to worrying about the person they care for. Significant numbers reported to direct impacts on their own personal wellbeing such as feeling tired (69%), getting stressed (58%) and getting depressed (42%). Many also reported that their social relationships suffer (35% not able to go out with friends, 62% not able to have friends round). Although relatively few (8%) said that they miss school there is no doubt that school life is affected, with 35% missing homework/deadlines, 27% late for school.

	Being A Carer Has Effect	
	Count	% Total
Worrying about the person you care for	22	85%
Not being able to out with friends	9	35%
Missing homework/coursework deadlines	9	35%
Not being able to go to a friend's house for a sleepover	7	27%
Not being able to have friends round to your house	16	62%
Not being able to do after school activities	5	19%
Being tired	18	69%
Late for school	7	27%
Missing school	2	8%
Getting stressed	15	58%
Getting depressed	11	42%

Source: Solihull Young Carers Survey 2013

### Other Young Carer Survey Feedback

In April 2014 they were also surveyed as part of a joint piece of work between the Young Carers Service and a GP practice, the purpose of this was 'to inform GP's of how they can

better support young carers in Solihull, from the voices of young carers themselves'. The young carers that took part in the survey told us that:

- 61% are in touch with their doctor
- 77% have appointments at the surgery
- 19% have spoken to their doctor on the phone
- 74% did not know that they could see the doctor by themselves, confidentially from the age of 12
- 13% have had bad experiences of going to see the doctor (usually with the person they care for)
- 58% go to the doctor with the person they care for.

When asked how they thought doctors could encourage young people to contact them if they were worried about their health or need advice, there was a variety of answers which included suggestions such as:

- Making sure everything is explained in plain English
- Be more approachable, show more support, not judgmental
- Be available online to talk to, phone up or send letters occasionally

As part of the Health Related Behaviours Questionnaire (HRBQ) in 2016, children and young people in Solihull schools were asked a number of questions some of which related to caring responsibilities. In years 4 and 6 16% of students said that they spent time at home looking after someone. In years 8 and 10 this rose to 33% and (36% boys and 31% girls). Among this age group 26% said they looked after someone on a regular basis but only 5% identified themselves as a young carer and 7% did not know.

## Section 5: The Caring Experience

This section provides an overview of the caring experience and the impact that the role can have on the life of the carer. Particular focus is placed on the experience of care during times of transition or crisis and the particular challenges faced by some specific groups of carers.

### Key Points in the Caring Journey

A report by the Royal College of General Practitioners (RCGP)<sup>18</sup> notes that the caring experience is heightened at times of transition and that contact with services is particularly critical at these points. This includes being provided with the right information and advice at the right time, an issue identified in consultation with Solihull carers who pointed out that information of different kinds will be needed by carers at different points/events in their lives, e.g. diagnosis, hospital discharge, thinking of giving up work (see section 4 What Solihull Carers Are Telling Us).

The RCGP identifies the following key transition points:

- Becoming a carer;
  - The need to recognise that the impact on the carer can vary significantly, particularly between cases where the onset is sudden (e.g. due to injury or a sudden diagnosis) and where the caring role emerges more gradually (e.g. due to deterioration in a pre-existing condition).
  - Early identification is vital in enabling those taking on a caring role to access the support they require and ameliorate the negative financial, emotional and health impacts of caring (see below).
- Dealing with crisis and urgent care (see below);
  - Emergency admissions can be the first sign a carer is not coping;
  - Important to invest in proactive planning to prevent unplanned admissions.
- Discharge from hospital in-patient care (see below);
  - Early discharge can cause carers anxiety and upset - especially if the person is in pain. It is important that they are provided with support from the medical team to help them to know what to do in an emergency.
- Rapid deterioration of the person or carers health;
- After caring is over;
  - As with becoming a carer, the impact on the carer can vary depending the length and complexity of the caring responsibility, the relationship between the carer and the cared for person and the reason (e.g. death, a crisis event, or gradual deterioration).

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<sup>18</sup> Royal College of General Practice (2013), Commissioning for carers. Available at <http://www.rcgp.org.uk/clinical/clinical-resources/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx>

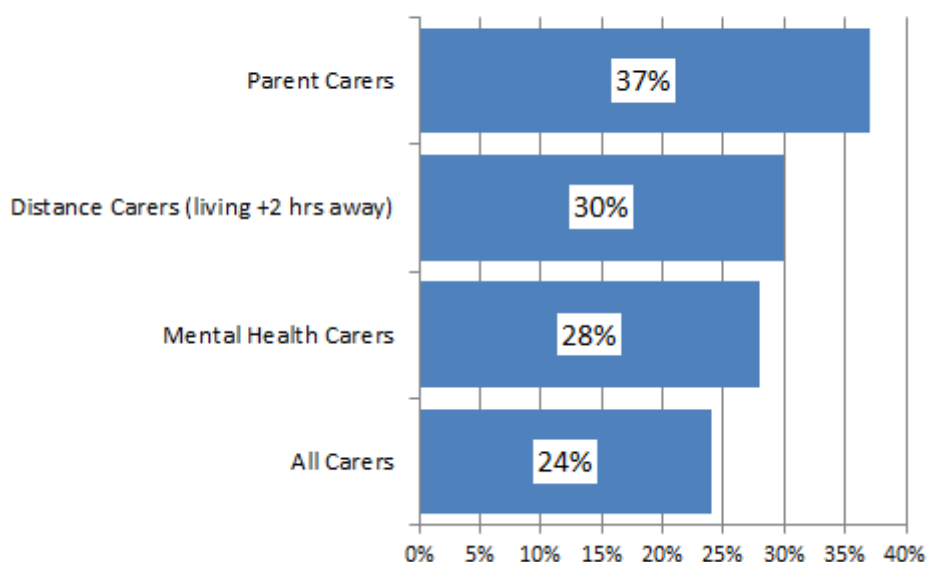


## Identifying Carers

A recent report by Carers UK<sup>19</sup> emphasises the importance of early identification, with the following key findings:

- The majority of carers take years to recognise their caring role;
  - Over half of carers (54%) took over a year to recognise their caring role;
  - Almost one in four carers (24%) took over 5 years to identify as a carer, and nearly one in ten (9%) took over 10 years.
- Some groups of carers, such as parent carers, mental health carers and distance carers, take longer than average to identify their role.

### Proportion of Carers Taking More Than Five Years to Identify Themselves as a Carer



- Not recognising a caring role is a significant barrier to accessing support;
  - 91% of carers said they missed out on financial or practical support (or both) as a result of not identifying as a carer.
- The impact of missing out on support due to not identifying as a carer is significant, of those who didn't identify themselves as a carer immediately;
  - 50% said that missing out on support had an impact on their physical health;
  - 78% suffered from stress and anxiety as a result of missing out on support;
  - 61% said missing out on support put a strain on their relationships with friends and family;
  - 52% missing out on support impacted negatively on their finances;
  - 42% said missing out on support had caused them to give up work to care.

The report does note that there has been an increase in the number of people who recognised their caring role within the first year of providing care in the 10 years between

<sup>19</sup> Carers UK (2016): Missing Out. The Identification Challenge

2006 and 2016, but argues that more needs to be done by services and within the community. Specific recommendations for improving early identification include:

- A new duty on the NHS and education professionals to put in place policies to identify carers and to promote their health and well-being.
- Development of education, information and training for a range of frontline professionals to increase knowledge and signposting of carers.
- Improved access to information and advice for carers.
- Employers should look at measures they can take to identify and support carers in the workplace.
- Public awareness campaigns to improve understanding and recognition of caring.

### **Emergency Admissions and Hospital Discharge**

Hospital admissions can be an indication of a breakdown in the caring relationship, because the carer is no longer able to care, often as a result of the strain of caring causing physical or mental ill-health. There is evidence to suggest that a significant number of admissions are due to problems associated with the carer rather than the person admitted. One study found that problems associated with the carer contributed to readmission in 62% of cases<sup>20</sup>.

A whole systems study tracking a sample of people over 75 years old who had entered the health and social care system, found that 20% of those needing care were admitted to hospital because of the breakdown of a single carer on whom the person was mainly dependent.

A survey and report by Carers UK<sup>21</sup> expands on the role of carers in reducing the use of A&E services, as well as the numbers of emergency admissions and delayed discharges of care from hospital and emphasises how critical this can be such events can be in the caring journey.

The majority of carers who used emergency services (999 or a visit to A&E) did so because they knew that urgent care was need, although 18% did so because they couldn't access out of hours GP or district nurse provision with a further 9% not knowing where else to go.

The majority of those caring for someone who had an emergency admission said it was unavoidable. Among the 59% where this was not the case the amount and quality of the care provided for the person admitted was most frequently cited. However, better access to primary care services (GPs, district nurses) and other wider community determinants such as more suitable housing (including equipment & adaptations and telecare) were also prominent factors. Importantly, 32% said that better support for themselves as a carer could have prevented admission (higher among those with non-disabled childcare responsibilities).

The report notes the national rise in delayed transfers of care and the proportion that are attributable to social care (especially those awaiting a package in their own home) and the additional burden and cost placed on the NHS as a result. Carers are a vital part of the discharge process, both in preventing any delay and in preventing unnecessary

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<sup>20</sup> Williams, E, Fitton, F (1991), 'Survey of carers of elderly patients discharged from hospital'. British Journal of General Practice, 41, 105-108.

<sup>21</sup> Carers UK (2016): Pressure Points: carers and the NHS

readmissions to hospital. A survey of carers who have gone through the discharge process found:

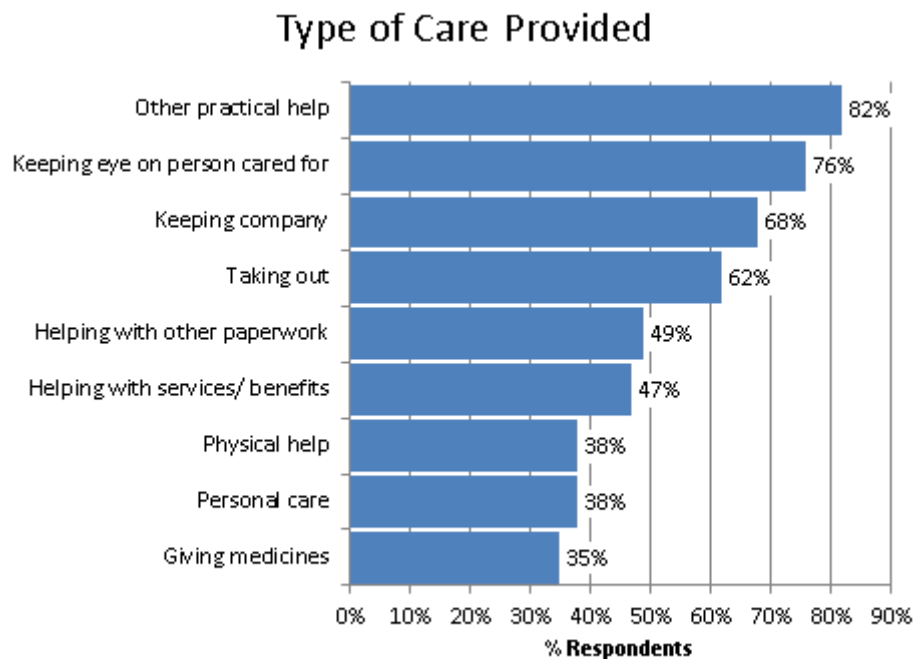
- 58% felt the person they care for was discharged too early (exacerbating the risk of readmission and potentially impacting on the wellbeing of the carer);
- 26% of carers said they were not consulted during the discharge process and a further 33% consulted only at the last minute;
- 59% said that they did not have a choice in starting to care when the person left hospital, rising to 73% among those who were not consulted during the discharge process.

These findings are important because, as the report notes, coming out of hospital is a critical moment for many families, often the start of their caring role or a deterioration in the condition of the person they care for. The discharge process should therefore be a key time to ensure that carers have the support they need in the short-term and that they know how to find out more about their rights to support. Without being connected early to support, carers can damage their own health in the longer term, become isolated and see their employment and finances affected.

## The Type of Care Provided

Carers provide a wide range of care and support for the people they care for depending on the condition of the cared for person, their own personal circumstances, where the care takes place (in their own household and elsewhere) and the degree of care services accessed.

The chart below shows the most commonly cited types of care provided by respondents to the NHS Survey of Carers in Households 2009/10.

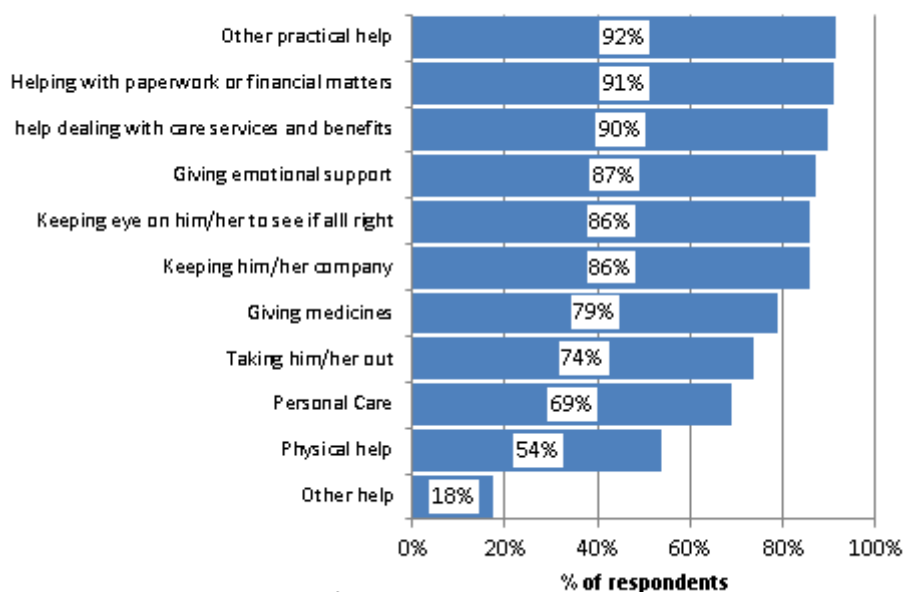


The Solihull Carers Survey 2016/17 also asked respondents about the type of care provided, although it should be noted that as this group, unlike the broader NHS survey, is drawn

exclusively from those who are known to social care services the type of care that they provide is likely to be more intensive. However, from this survey it is clear that many carers help with all aspects of the cared for persons life (from personal care to emotional support) and that many people who are themselves frail or suffering from ill health perform physically demanding tasks. In summary:

- At least 50% of carers helped the person they care for each of the ten care tasks that were surveyed, with more than 85% of carers undertaking each of the following:
  - Helping with paperwork or other financial matters (91% of respondents);
  - Help dealing with care services or benefits (90%);
  - Helping with paperwork or other financial matters (91%);
  - Giving emotional support (87%);
  - Keeping cared for person company (86%);
  - Keeping an eye on the cared for person to see if they are alright (86%).
- Although a smaller proportion (54%) of carers say they provide physical support for the person they care for it is worth noting that 55% of those who say that they have an illness, disability or health condition do so as well as 51% of those aged 75 years and over.

### Over the last 12 months, what kinds of things did you usually do for the person you care for



Source: SMBC Carers Survey 2016/17

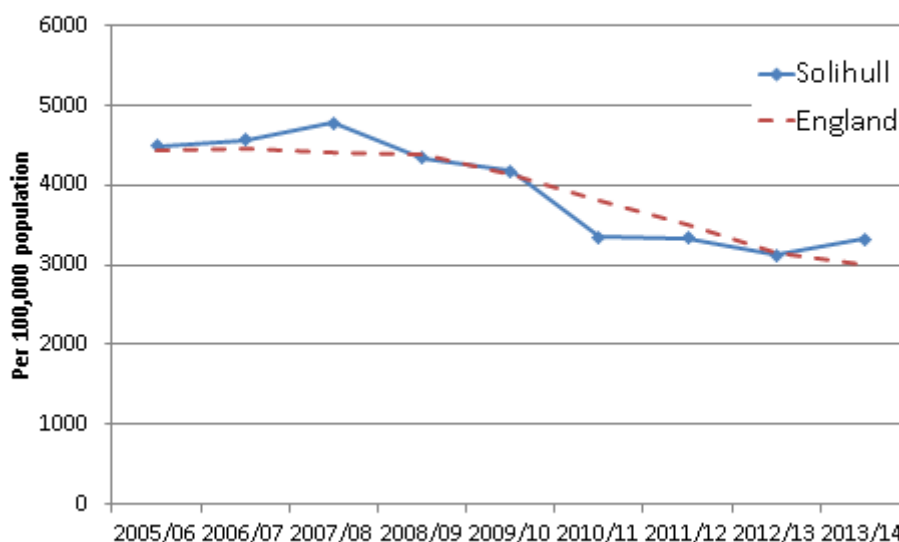
## Practical Support and Access to Services

The availability of services and practical support for carers needs to be considered in the light of broader trends in adult social care provision, with sharp reductions in older people receiving funded care the most notable feature. A report by the Nuffield Trust and King's Fund<sup>22</sup> notes that nationally there has been a big reduction in the numbers of older people

<sup>22</sup> Humphries R, Thorlby R, Holder H, Hall P, and Charles A (2016) Social care for older people: home truths. Research report. The King's Fund and Nuffield Trust.

receiving local authority-funded social care – from more than 1.1 million in 2009 to 853,615 in 2013/14 – a fall of 26%. It is likely that the trend will have continued in 2014/15 and beyond but changes to data collection unfortunately mean that there is no a longer a comparable figure. The number of people aged between 18 and 64 years getting help has also fallen, but not by as much. As the chart below shows a similar pattern is evident in Solihull.

**People Receiving Local Authority Funded Social Care  
2005/06 – 2013/14**



Source: NASCIS

This reduction in the provision of adult social care is contributing to a rise in unmet need among older people. For instance, it is estimated that more than a million people who have difficulties with the basic activities of daily living, such as getting out of bed, washing and dressing, now receive no formal or informal help at all. That is an increase of 100,000 in one year alone<sup>23</sup>; an unmet need which will increasingly be met by family carers.

The wider pressures on adult social services may also be undermining some of the intended benefits for carers established in the Care Act 2014, with a recent assessment by the Carers Trust<sup>24</sup> concluding that the Care Act had made ‘little or no difference’ to many carers. In the latest Carers UK State of Care survey<sup>25</sup>, one in three carers (34%) reported a change in the amount of care and support services they or the person they care for receive. Of these, more than half (59%) saw a reduction in care and support services due to cost or availability; this includes 13% who said a service was closed with no replacement offered.

The State of Care report also emphasises the importance of practical support in helping to maintain carers in their caring role and to ensure that they are able to live a healthy and balanced life. The survey shows that 78% of carers buy or receive some form of practical support with their caring role, be that equipment, technology, a break from caring or help from family and friends. However, 20% who are providing 50 hours or more of care each

<sup>23</sup> Age UK (2017): Health and Care of Older People in England 2017

<sup>24</sup> Carers Trust (2016). Care Act for carers: one year: lessons learned, next steps

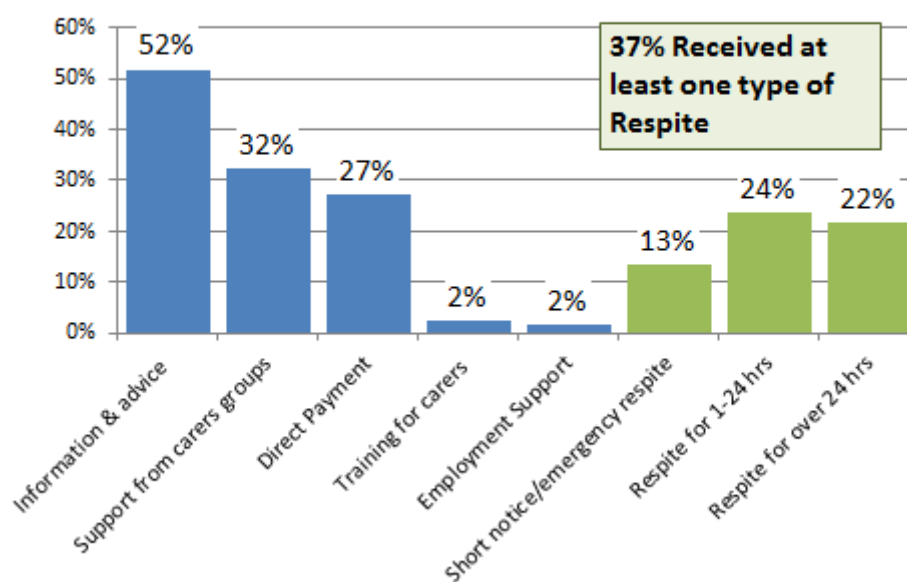
<sup>25</sup> Carers UK (2016): The State of Care

week are receiving no practical support with their caring role. The detailed breakdown shows the diverse range of support received:

- 48% have practical support in the form of equipment in the home of the person they care for, such as hoists, grab rails or easy grip handles;
- 24% use technology to help their caring role;
- 9% have support from care workers;
- 29% have help from family or friends;
- 18% have a break from caring for themselves;
- 22% have a Motability vehicle, which enables them to get out and about with the person they care for;
- 19% looking after someone with a learning disability use a day centre.

Of the Solihull carers responding to the 2016/17 Carers Survey, 52% (132 carers) said that they had received information & advice in the last 12 months, 32% (84 carers) had received support from carers groups or someone to talk to in confidence, but just 2% had received either training for carers or support to keep them in employment. In addition to these direct carers services, 37% of respondents said that the person that they care for accessed some sort of respite care during the last year – including from 24% receiving a break from caring for more than 24 hours, 22% having a rest from caring for between 1 and 24 hours (eg. a sitting service) and 13% receiving short notice or emergency respite.

**Solihull Carers Receiving Direct or Indirect Support in Last 21 Months**



The survey also asks carers whether they feel encouraged and supported in their caring role. The proportion who feel encouraged and supported fell to 24% in 2016/17 with those who feel that they have no encouragement also rising slightly to 25%. The overall response on this measure is markedly worse than in 2009/10.

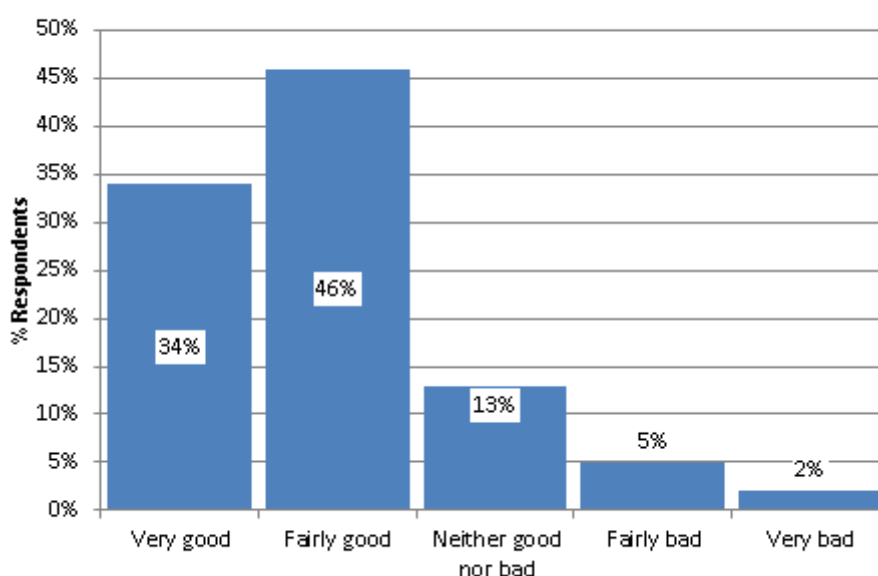
	% of Respondents			
	2016-17	2014-15	2012-13	2009-10
I feel I have encouragement and support	24%	37%	36%	50%
I feel I have some encouragement and support but not enough	52%	41%	45%	40%
I feel I have no encouragement and support	25%	23%	19%	10%

*Source: SMBC Carers Survey 2009-10 to 2016-17*

## Quality of Life

Nationally, the NHS Survey of Carers in Households 2009/10 found that a large majority of carers (80%) regard their overall quality of life as being good with relatively few saying it is bad (7%). Carers caring for 20 hours+ and those looking after the cared for person in the same household are more likely to say that their quality of life is bad (11% and 9% respectively).

### Carers Self Reported Quality of Life



*Source: Survey of Carers in Households – NHS The Information Centre for Health & Social Care*

Despite this relatively positive quality of life indicator it should be noted that the Carers UK State of Caring survey indicates that 54% of carers think that their quality of life will get worse in the next year, compared with 6% who think it will get better<sup>26</sup>.

## Health & Wellbeing

Research evidence shows that a caring role can have a negative impact on mental and physical health as well as emotional wellbeing, with carers at greater risk of developing long-term or chronic conditions such as hypertension and heart disease as well as being prone to

<sup>26</sup> Carers UK (2016): State of Caring 2016

injuries resulting from manual handling. These negative health and wellbeing impacts can vary depending on the personal circumstances of the carer, the condition of the cared for person and the relationship between the two. Carers who are more vulnerable to health problems are women, elderly or very young people, those with pre-existing poor physical health, carers with arduous duties and those with few social contacts or support<sup>27</sup>. The impact of caring is likely to be exacerbated the longer a person is in the caring role and because carers often regard their own health needs as secondary to the person they care for. In this respect, research shows that carers are less likely to engage in preventative health behaviours (e.g. health checks and treatment)<sup>28</sup> with Carers UK reporting instances of carers discharging themselves early from hospital because of the absence of alternative care.

In a recent survey by Carers UK<sup>29</sup> 82% of those surveyed saying that caring has a negative impact on their health. 41% said that they had experienced an injury or their physical health has suffered as a result of caring, although this was a smaller proportion than those reporting negative mental health and emotional impacts. For instance, 84% said that they feel more stressed, 78% reported feeling more anxious, and 55% stated that they have suffered from depression as a result of their caring role.

At 52%, the proportion of carers saying that their health had been negatively impacted as a result of caring was much lower in the NHS Survey of Carers in Households 2009/10, although the results show that the proportion was higher among those caring for 20 hours or more (66%), those caring for someone in their own household (62%) and those looking after a family (63%). As with the Carers UK survey, respondents were more likely to report negative mental and emotional effects rather than physical ones.

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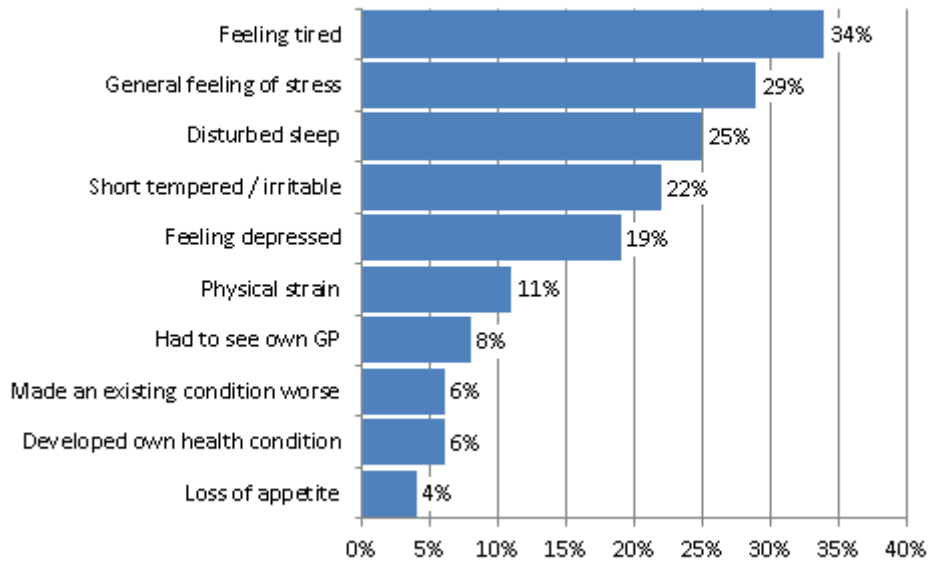
<sup>27</sup> Cormac, I. and Tihanyi, P. (2006) Meeting the Mental and Physical Healthcare Needs of Carers. *Advances in Psychiatric Treatment* (2006), vol 12.

<sup>28</sup> Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C. & Jackson, S. (1997). Health effects of caregiving. *Annals of Behavioral Medicine* 19.

<sup>29</sup> Carers UK (2015): *The State of Caring*



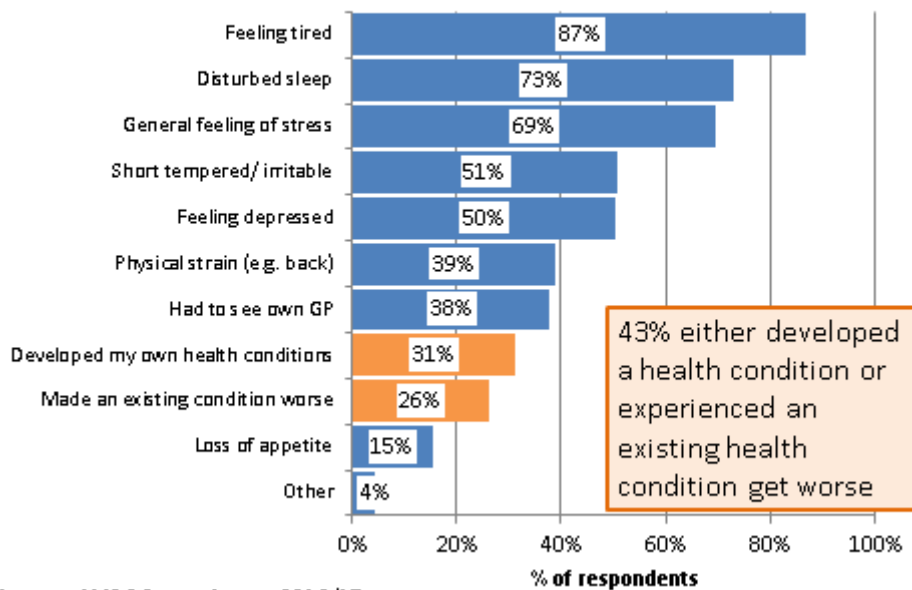
## Impact of Caring on Carer



Source: Survey of Carers in Households – NHS The Information Centre for Health & Social Care

The same question was asked in the 2016/17 Solihull Carers Survey and although it should be noted that as it is based on those known to social services resulting in a sample skewed towards those who have a more intensive caring role, the results are broadly the same with wellbeing issues more prominent than physical health problems. That said, 43% of Solihull respondents either developed a health condition of their own or felt that a pre-existing condition had deteriorated due to their caring role.

## Impact on Health & Wellbeing of Carer



Source: SMBC Carers Survey 2016/17

Locally the Census provides the most comprehensive overview of how all carers, including those not in contact with services, regard their own health. In Solihull 1,383 carers described

their general health as either bad or very bad, which equates to 5.7% of all carers compared to the England average of 6.6%. A further 20% say that their health is fair with just over 74% describing it as either good or very good.

Self Reported Health Status	Solihull Count	% of Carers		
		Solihull	England	West Midlands
Good or Very Good	17,874	74.2%	72.7%	71.1%
Fair	4,847	20.1%	20.7%	21.8%
Bad or Very Bad	1,383	5.7%	6.6%	7.1%

Source: ONS Census 2011

Only a slightly higher proportion of Solihull’s carers describe their health as bad or very bad than the rest of the population (5.7% compared to 4.9%), although carers are significantly more likely to say that their health is just fair (20% compared to 12%).

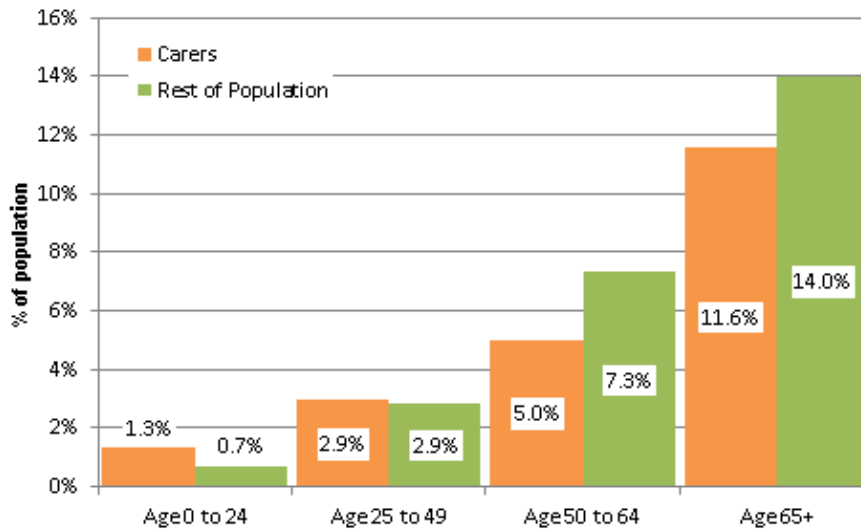
**Relative Health of Carers and Rest of Population in Solihull**



Source: ONS Census 2011

Unsurprisingly the proportion of carers that state that their health is either bad or very bad increases with age (12% of those aged 65+ compared to just 4% of those under 65 years). However, it does not appear that the burden of providing care later in life is, in itself, necessarily detrimental to health, as the proportion carers aged 65+ who say their health is bad or very bad is actually lower than the rest of the population in this age band (12% compared to 14%). This is consistent with the pattern across England as a whole.

## Population with Bad or Very Bad Health in Solihull

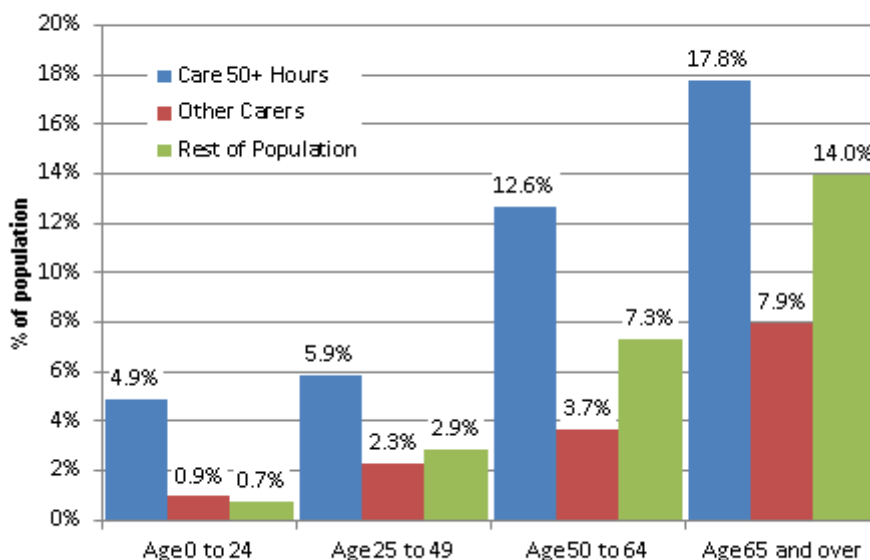


Source: ONS Census 2011

The number of hours of care that an individual provides is a more important determinant, with those caring for 50 hours or more per week at far greater risk of poor health than those caring for fewer hours.

Nearly 13% of carers in Solihull who provide 50+ hours of care per week state that their health is either bad or very bad compared to 3.9% among other carers and 4.9% among those who provide no care. This additional health risk attached to those who provide 50 hours+ care when compared with both non-carers and those who care for less than 50 hours is evident among all age groups in both Solihull and England.

## Population With Bad or Very Bad Health in Solihull

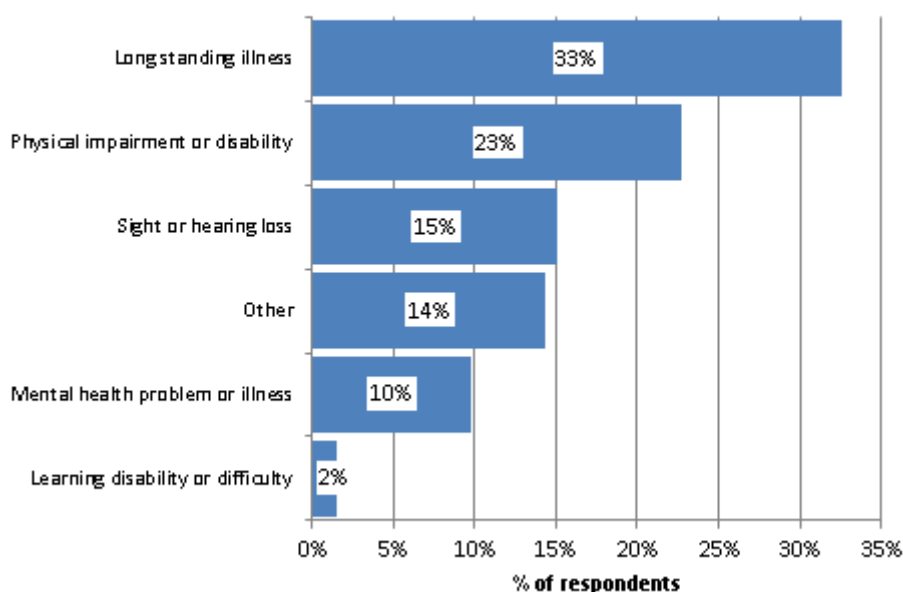


Source: ONS Census 2011

The statutory Carers Survey of 2016/17, which surveys a sample of carers who have been assessed or reviewed by SMBC in the previous 12 months, asks specifically which, if any, health conditions that carers themselves have. 58% of Solihull respondents indicated that they had at least one health condition or impairment, although it should be noted that this survey focuses of those known to social care services and therefore more likely to have intensive caring responsibilities than all of the carers captured within the Census.

The most common condition is a long-standing illness (33%), followed by physical impairment or disability (23%) and sight or hearing loss (15%). A far smaller proportion have a mental health problem/ illness (10%) or learning disability/difficulty (2%).

### Do you have any of the following



This survey also shows that many carers suffer from multiple health or disability conditions, with 24% citing more than one condition and 8% three or more.

## Employment

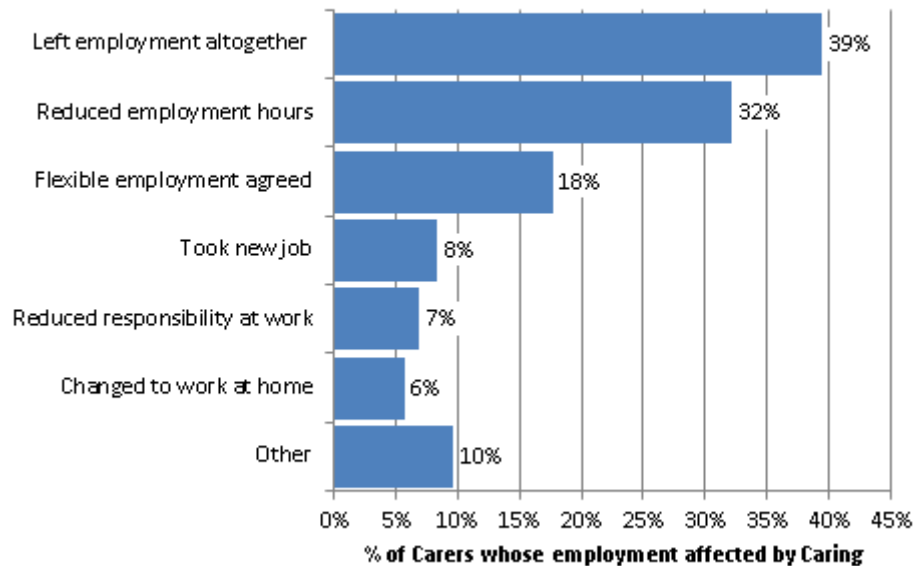
It is estimated that almost 15% of all employees care for a family member. A range of survey evidence reveals that caring can significantly impact on the ability of carers to take up or remain in employment. For those who remain in a employment caring responsibilities can negatively affect their working life, with 17% of respondents to a Carers UK survey<sup>30</sup> saying that they had taken a less qualified job or turned down a promotion and many taking annual leave (70%) or working overtime (48%) to compensate for their caring role.

26% of respondents aged 70 and under to the NHS Survey of Carers in Households 2009/10 said that their caring role had affected their ability to take up or stay in employment, with this proportion rising significantly among those caring for 20 hours or more a week (40%), those who live in the same household as the cared for person (38%) and those working part-time (35%). Among those whose employment had been affected 39% said that they had left

<sup>30</sup> Carers UK (2016): The State of Caring

employment because of their caring responsibilities and a further 32% had reduced their employment hours.

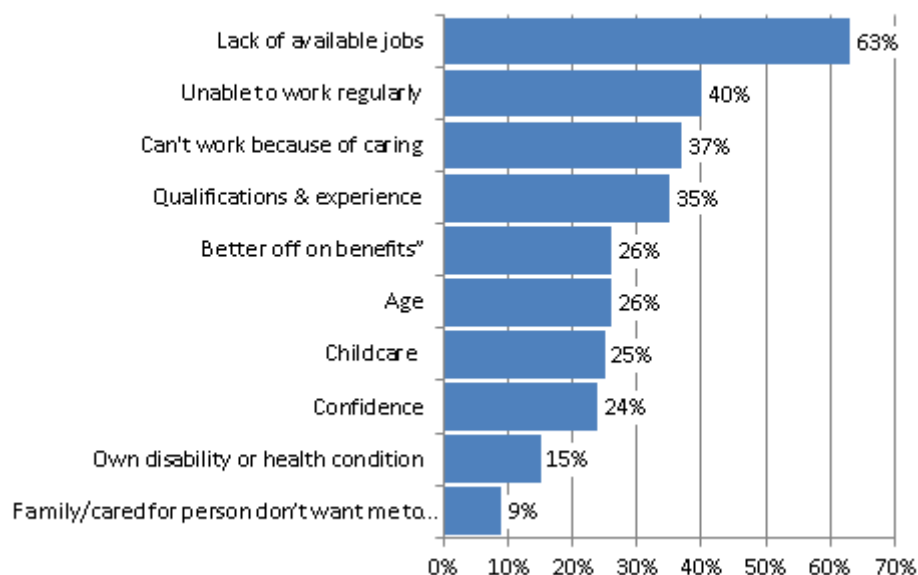
## Effect of Caring on Employment



Source: Survey of Carers in Households – NHS The Information Centre for Health & Social Care

The most commonly cited barrier to employment cited by respondents was the lack of available job opportunities (63%), although issues directly relating to caring responsibilities were also prominent: unable to work regularly (40%), can't work because of caring (37%).

## Barriers to Employment Carers Aged Under 70



Source: Survey of Carers in Households – NHS The Information Centre for Health & Social Care

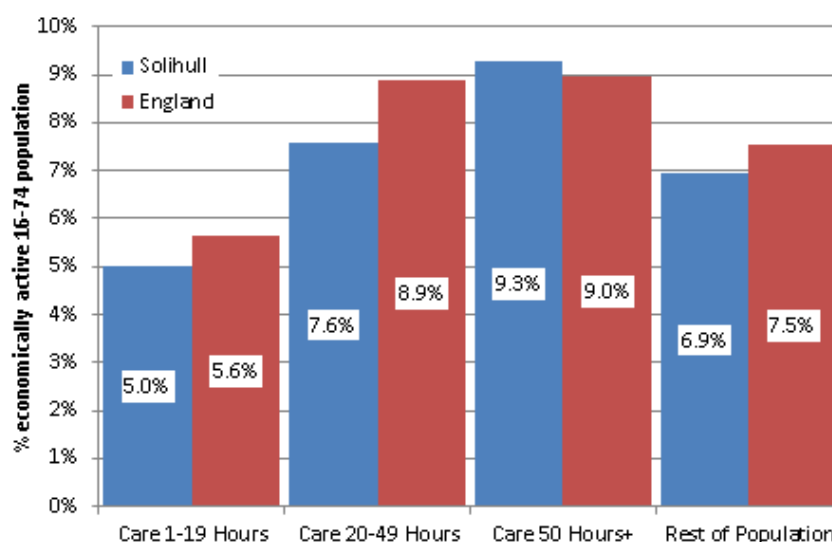
Locally, the Census shows that, with the exception of those that care for 50 hours or more per week, Solihull employment rates are higher among carers than the rest of the population.

However, unemployment is higher among carers who care for both 20-49 hours (7.6%, 116 individuals) and 50 hours+ (9.3%, 145 individuals). This is consistent with the pattern across England as a whole.

% of Economically Active Population in Solihull				
	Cares 1-19 Hours	Cares 20-49 Hours	Cares 50+ Hours	Rest of Population
Employed	93.6%	91.1%	89.8%	89.6%
Unemployed	5.0%	7.6%	9.3%	6.9%
Full-Time Students	1.4%	1.3%	0.9%	3.5%

Source: ONS Census 2011

### Comparative Unemployment Rates



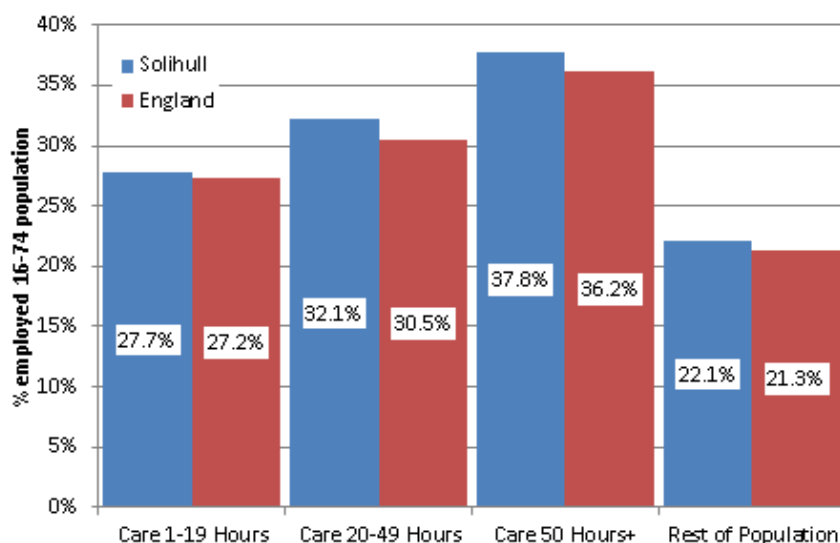
Source: ONS Census 2011

The carers employment profile is notably different to that of the rest of the population with part-time employment and self-employment more common, particularly among those caring for more than 50 hours per week.

% of Employed Population in Solihull				
	Cares 1-19 Hours	Cares 20-49 Hours	Cares 50+ Hours	Rest of Population
Full-Time Employee	56.4%	53.7%	45.6%	63.5%
Part-Time Employee	27.7%	32.1%	37.8%	22.1%
Self-Employed	15.9%	14.2%	16.7%	14.4%

Source: ONS Census 2011

## Comparative Part-Time Employment Rates



Source: ONS Census 2011

While caring responsibilities undoubtedly present a challenge for carers in terms of labour market participation, a range of research suggests that there are some positive trends with respect to increasing job opportunities for carers. For instance, a survey by Employers for Carers conducted on behalf of Carers UK<sup>31</sup> suggests that employers are increasingly recognising caring as a key issue for workforce recruitment and retention, with the findings showing that:

- The majority of employers considered that supporting carers in their workforce had either a major or some benefit in their ability to attract and retain staff, reducing recruitment and training costs, reducing sick leave and absenteeism, increasing productivity and improving service delivery, producing cost savings and increasing staff morale, improving staff engagement, people management and team working;
- 56% of employers said that they address carer support on a case-by-case basis and 44% through organisation wide policies, however, many of these suggested that most of the times they use a mix of these methods;
- Flexible working (94%), flexible/special leave (83%) and remote working (50%) were among the most popular ways employers used to support carers in their workforce, followed by in-house information/signposting (40%) and other workplace support/employee benefits (29%).

In a similar vein work by Sheffield Hallam University's Centre for Social Exclusion<sup>32</sup> points to the fact that more inclusive employment legislation is being supported by underlying changes in the structure of the labour market. Although written at a time when the number of jobs in the economy had been increasing for a number of years, the report suggests that an ageing workforce should provide job opportunities for working age carers and other excluded groups. This is particularly the case as employers become more attuned to the needs of

<sup>31</sup> Carers UK (2013): Employers Business Benefits Survey

<sup>32</sup> Yeandle et al (2006): Who Cares Wins the Social and Business Benefits of Supporting Working Carers

flexible working and technology driven alternatives such as home working become more viable.

Responses to the Carers Survey suggest that more work needs to be done in terms of employment support. Excluding those who are retired, 47% of Solihull respondents in 2016/17 said that they were not in employment due to their caring responsibilities, with a further 11% saying that they do not feel supported by their employer and 7% saying that they are self-employed but unable to balance this with their caring responsibilities.

<b>Thinking about combining your paid work and caring responsibilities, which of the following statements best describes your current situation?</b>		
	Number	% Not Retired
Not in paid employment due to caring responsibilities	58	47%
In paid employment - feel supported by employer	26	21%
In paid employment - don't feel supported by employer	14	11%
In paid employment - don't need support from employer	8	7%
Self-employed - able to balance work & care	9	7%
Self-employed - unable to balance work & care	8	7%
Total	123	
<i>Source: SMBC Carers Survey 2016-17</i>		

## Financial Burden

In the 2016/17 Carers Survey 55% of Solihull respondents said that their caring role had caused financial difficulties in the last 12 months (43% to some extent, 12% a lot). This is a theme supported by a range of national research.

A recent survey by Carers UK<sup>33</sup> highlights many of the financial pressures faced by carers as a result of their caring role, with 44% of carers surveyed saying that they have been in debt as a result of caring. In addition 52% say that financial concerns are affecting their health. In part this is because carers have a reduced capacity to earn when compared with non-carers, but also because they incur substantial costs as a result of the illness or disability of the person they care for. A separate report details many of the extra costs faced by carers<sup>34</sup>:

- Higher heating and electricity bills: as families are at home all day and disabled, ill and older people need to be kept warm.
- Higher basic household costs: incontinence can mean washing bedsheets several times a week or even every day.
- Specialist equipment, foods and medicines: these range from everyday costs of food and incontinence pads, to big costs for aids and adaptations.
- If families do not qualify for social care support, they may face bills of hundreds of pounds for replacement care if they want to take a few days off from caring.
- Big travel and parking charges from frequent trips to hospital and GPs.

Financial difficulties have resulted in many carers surveyed in the State of Caring cutting back on essentials:

<sup>33</sup> Carers UK (2013) The State of Caring 2013

<sup>34</sup> Carers UK (2011) The Cost of Caring: How Money Worries Are Pushing Carers to Breaking Point



- 41% of those struggling are cutting back on essentials like food and heating;
- 14% have cut back on care support services;
- 45% have cut back on food;
- 44% have cut back on heating;
- 74% have cut back on seeing friends and family;
- 44% have cut back on phone use.

Fuel poverty also appears to be a significant issue, with 58% of carers surveyed saying that they spent at least 10% of their income on energy bills. Although the statistics are not directly comparable as they are based on households rather than individuals, ONS figures from 2011 provide some context, showing that on average less than 15% of households in the UK are fuel poor.

Alongside employment issues, Carers UK attribute some of the financial hardship faced by carers to not getting the right information at the right time, with 42% of those surveyed feeling that they had missed out on financial support as a result of not getting the right information and advice early enough. This would fit with the analysis of Carers' Allowance take up, which indicated that around 35% of those eligible in Solihull were missing out on payments.

A report by Carers UK<sup>35</sup> based on a national survey conducted as part of the Carers, Employment and Services study (University of Leeds) argues that while affluence does not solve all carers' problems and difficulties, poverty undoubtedly causes some carers additional stress and worry. In addition it notes that within the survey those carers who identified themselves as financially struggling to make ends meet represent a distinct and significant sub-group of the carer population and are more likely to be:

- in poor health (34%);
- unqualified (21% have no formal qualifications);
- caring for 20 or more hours per week (88%, with 66% caring 50+ hours per week);
- caring for a child aged 19 or under (37%);
- caring for someone with a learning disability (42%);
- caring for someone with a mental health problem (27%);
- receiving some free services (as a carer or as services to the person cared for).

## Social Isolation and Personal Relationships

Research from the US<sup>36</sup> found that, although providing care is a taxing experience, it also has positive and rewarding side-effects. For example 47% those surveyed strongly agree that they appreciate life more as a result of their caregiving experience and 48% report that it has made them feel good about themselves. Furthermore, it was found that caregiving can lead carers to feel useful or proud, or experience personal growth or an enhanced relationship with the care recipient and other family members. However, the report also cites research showing that, for many carers, the amount of time they have to devote to providing care as well as the resulting physical and emotional strain can lead to a loss of self identity,

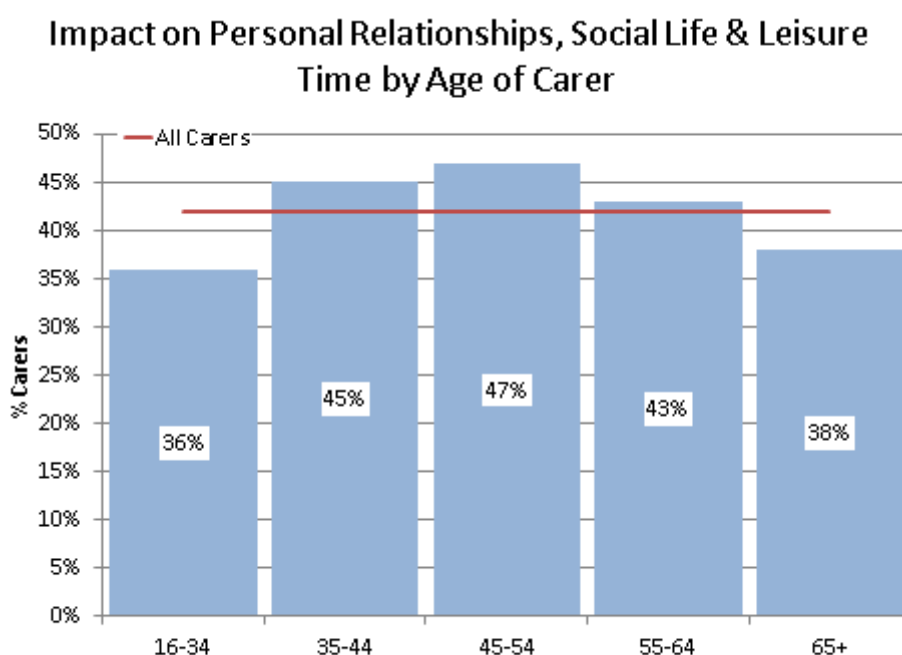
<sup>35</sup> Yeandle et al(University of Leeds 2007): Diversity in Caring: Towards Equality for Carers

<sup>36</sup> Cited in How Do Family Caregivers Fare? A Closer Look at Their Experiences: Georgetown University (2005)

lower levels of self esteem and depression. These risks and the need to address them are acknowledged in UK Government strategy<sup>37</sup>:

*Carers should have the opportunities and space they need to participate in activities outside their caring role. They should be free to have an identity that is separate from that of the people they support. Carers have the right to expect these freedoms, which others take for granted, and to avoid the social exclusion that may result from having no life outside caring.*

Evidence from the NHS Survey of Carers in Households 2009/10 suggests that this is often not the case, with 42% of those surveyed saying that caring had affected their personal relationships, social life and leisure, rising to 50% among those who live in the same household as the cared for person and 54% among those who care for 20 hours or more per year. Interestingly there was a relative narrow range across age bands.



Source: Survey of Carers in Households – NHS The Information Centre for Health & Social Care

Among the most common impacts on personal relationships, social life and leisure cited by respondents were less time for leisure activities (69%), too tired to go out (32%) and unable to go on holiday (23%).

Preliminary results from the Solihull Carers Survey support this. In 2016/17 21% of Solihull respondents said that they have little social contact and feel socially isolated, representing a marked increase compared with previous years. England wide results were not available at the time of writing, although it should be noted that in previous surveys Solihull results have been less favourable than the national average on this measure.

<sup>37</sup> "Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own", Department for Health, June 2008.

	2016-17	2014-15	2012-13	2009-10
I have as much social contact as I want with people I like	21%	37%	35%	47%
I have some social contact with people but not enough	58%	50%	48%	42%
I have little social contact with people and feel socially isolated	21%	13%	18%	11%
<i>Source: SMBC Carers Survey 2009-10 to 2016-17</i>				

Similarly, 21% of Solihull respondents say that they don't do anything they value or enjoy with their leisure time, a figure that has risen in each of the last three surveys.

	2016-17	2014-15	2012-13	2009-10
I'm able to spend my time as I want, doing things I value or enjoy	12%	18%	18%	24%
I do some of the things I value or enjoy with my time but not enough	67%	64%	65%	67%
I don't do anything I value or enjoy with my time	21%	18%	17%	9%
<i>Source: SMBC Carers Survey 2009-10 to 2016-17</i>				

## The Experience of Specific Carer Groups

### **Young Carers**

A recent report by the Children's Commissioner<sup>38</sup> notes that the official figures from the 2011 Census substantially under-estimate the number of young carers in England and that only a relatively small proportion of young carers receive support from their Local Authority (estimate 20%). This is supported by the findings of an early survey of school pupils that found that official data under-estimates the number of young carers by as much as 75% and that 1 in 12 up to the age of 18 have some form of caring responsibility<sup>39</sup>. Particular problems exist identifying the very youngest carers (including some under the age of 5), as well as those caring for someone with a substance misuse problem or where there is domestic violence in the home. A range of research<sup>40,41</sup> reasons for this under-estimation and concludes that it is due to a range of family related causes. These family issues are acknowledged in the Government report *Recognised, Valued and Supported*:

*Many young carers remain 'hidden' from health, social care and education services – partly as a result of those services needing to do more to identify them but also because of family fears that they will be taken into care or because the young people themselves are concerned about the reactions of others and bullying by their peers.*

<sup>38</sup> Children's commissioner (2016): *The Support Provided to Young Carers in England*

<sup>39</sup> BBC and Nottingham University (2010). Accessed via: <https://www.nottingham.ac.uk/news/pressreleases/2010/november/youngcarers.aspx>

<sup>40</sup> The Children's Society (2013) *Hidden from View: The Experience of Young Carers in England*

<sup>41</sup> Clarkson, Frank, Lucantoni, Fox (2008) *Emotional Support for Young Carers: Briefing Paper for Royal College of Psychiatrists*

A briefing by the Social Care Institute for Excellence<sup>42</sup> points out that assessing the impacts of caring on young carers is problematic because little of the research is based on comparative studies, making it difficult to assess to what extent outcomes are a result of caring responsibilities as opposed to other socio-demographic factors. Furthermore, it should also be noted that young carers are not a homogenous group, providing care in different circumstances and for people with different care needs. For instance a report by the Princess Royal Trust for Carers<sup>43</sup> notes that the impact of caring on young carers can be particularly acute for those caring for a parent with substance or alcohol misuse or mental health issues. Regardless of the limitations of research the majority of national studies have found that young carers themselves feel that their caring responsibilities have an impact on their life, describing how it affects their relationships, their school life and their feels of wellbeing. This is supported by the survey of young Solihull carers undertaken by the Carers Centre (see section 3 What Solihull Carers Are Telling Us). Many of the young people in this survey reported feeling worried, tired and stressed, with their caring role also impacting on their social relationships.

Extensive national research suggests that 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 can experience physical health problems associated with lifting and handling, family stress, identity issues, emotional distress and poverty. In fact research by Dearden and Becker<sup>44</sup> suggests that as many as one-third of young carers are involved in excessive or inappropriate caring such as emotional support and intimate personal care. However, it should be noted that a range of studies<sup>45,46</sup> highlight some of the positive impacts of caring experienced by some young people. For instance, many young carers report that caring gives them feelings of maturity, and a sense of closeness to both parents and family; they also value their responsibilities and consider them to be a source of practical life skills. Young carers are often happy to perform their role and can see it simply as providing support to the family, rather than something more onerous or distinct.

Caring responsibilities can have an impact on the physical health of the child, with many reporting feelings of tiredness and some, especially those where the cared for person has a physical disability, experiencing physical strain as a result of lifting. However, caring is more likely to have lasting impacts on the psychological health and emotional wellbeing of a child.

For instance, surveys of young carers found substantial numbers reporting stress, anxiety, low self-esteem and depression<sup>47,48</sup>. Other studies also found that substantial numbers of

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<sup>42</sup> Social Care Institute for Excellence (2005): The Health and wellbeing of Young Carers Briefing

<sup>43</sup> Princess Royal Trust for Carers: At What Cost to Young Carers?

<sup>44</sup> Dearden, C. and Becker, S. (2004): Young Carers in the UK

<sup>45</sup> Dearden C. and Becker S. (2000). Growing Up Caring: Vulnerability and Transition to Adulthood – Young Carers' Experiences

<sup>46</sup> Frank J. Tatum C. Tucker C. (1999). On Small Shoulders: Learning from the Experiences of Former Carers

<sup>47</sup> Banks P., Cogan N., Deeley S., Hill M., Riddell S., Tisdall K. (2001). Seeing the invisible children and young people affected by disability. *Disability and Society*, 16

<sup>48</sup> Dearden C. and Becker S. (1998). Young Carers in the United Kingdom: A Profile

young carers reported mental health and related problems, such as eating problems, difficulty in sleeping, and self harm<sup>49,50</sup>.

A national study of over 15,000 year nine pupils<sup>51</sup> (age 13 and 14) found that around 5% of young carers missed school because of their caring responsibilities, with one in three of those missing school doing so at least once or twice a month, which is broadly in-line with the small sample from the Solihull Young Carers Survey 2013 (8%). Other research suggests that even if young carers are able to attend school on a regular basis school work and attainment can be affected. For instance, Dearden and Becker<sup>52</sup> found that 27% of all secondary school-aged young carers and 13% of all primary school-aged young carers experienced some problems relating to academic progress and attainment, and/or social interactions in school, while a Barnardo's survey<sup>53</sup> found that 43% of young carers felt their school work was 'adversely affected' by their caring role. These findings are largely substantiated by a comparison of GCSE attainment<sup>54</sup>, in which it was found that the average total GCSE points score for a young person who had caring responsibilities in year 9 was 333, compared to 386 for young people who were not young carers in year 9; a difference of 53 points, equivalent to nine GCSE grades overall, or the difference between nine B's and nine C's.

Alongside a lack of time and opportunity to socialise, many studies have found that young carers are reluctant to do so, possibly due to anxieties about bullying<sup>55</sup>. Abraham and Aldridge<sup>56</sup> found that among their study group the older young carers who had on average undertaken a caring role for longer were less optimistic about the future, had poorer views of themselves, depleted levels of interest (in new things) and did not feel as close to others in their lives suggesting that prolonged social isolation can have lasting developmental impacts.

## Young Adult Carers

Although young adult carers, defined as being between the ages of 16 and 24 years, overlap with and share many of the same issues as young carers as a whole, they also represent a distinct and often hidden proportion of the carers population. Much of the existing research literature focuses on the additional pressures that caring places on the social and emotional transition from adult to childhood and the impact of caring on education, training and employment. Among the social challenges faced by young adult carers research by Fiona and Saul Becker<sup>57</sup> shows that:

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<sup>49</sup> Frank J., Tatum C., Tucker C. (1999). On Small Shoulders: Learning from the Experiences of Former Carers

<sup>50</sup> Cree V.E. (2003). Worries and problems of young carers: issues for mental health. *Child and Family Social Work*, 8 (4)

<sup>51</sup> The Children's Society (2013) *Hidden From View: The Experiences of Young Carers in England*

<sup>52</sup> Deardon C. and Becker S. (2004): *Young Carers in the UK*

<sup>53</sup> Barnardo's (2006) *Hidden Lives: Unidentified Young Carers in the UK*

<sup>54</sup> The Children's Society (2013) *Hidden From View: The Experiences of Young Carers in England*

<sup>55</sup> Social Care Institute for Excellence (2005): *The Health and wellbeing of Young Carers Briefing*

<sup>56</sup> Abraham, K. Alderidge j. (2010) *Who Cares About Me?: The Mental Well Being of Young carers in Manchester*

<sup>57</sup> Becker and Becker (2008): *Young Adult Carers in the UK Experiences, Needs and Services for Carers Aged 16-24*

- Just over a third of those surveyed reported having ‘strained relationships’ with the person(s) that they were caring for;
- Half of the sample said that they felt they had insufficient time for themselves this was particularly the case for those carers who were providing high levels of emotional care or where they were caring for more than one person;
- Emotional pressures and demands for care make it especially hard for young adult carers to leave home. Others choose not to leave in order to protect siblings from assuming a caring role;
- Young adult carers often chose friends and/or partners who were sympathetic and understanding of their situation. Several respondents spoke of the ‘burden of their maturity’ and how this affected their ability to make friends because it had made them different from their peers and restricted their ability to be spontaneous and carefree.

In terms of education, training and employment NIACE’s work with young adult carers<sup>58</sup> indicates that problems of balancing caring and studying experienced by children carers at school can continue on through to further and higher education. In a similar vein the Audit Commission noted in 2010 that for young people 16-18 having responsibilities as a carer was a factor that significantly increased their risk of being NEET (Not in Education, Employment or Training) and the risk of being NEET for more than six months was twice that of their peers. 75% of young adult carers identified in this work had been NEET at least once (compared with 25% of all young people) and 42% NEET for six months or more (compared with 10% of all young people).

Becker and Becker’s work found that although many find college study better and more flexible than school some young carers still reported leaving prematurely without completing their intended qualifications. It was also found that a combination of lower skills, the need for flexible working arrangements to accommodate caring responsibilities and low levels of confidence and self esteem can either increase risks of young adult carers being unemployed or of working in part-time or lower paid jobs. In turn this has a detrimental effect on young adult carer’s finances with many reporting that they also have to use their own money to subsidise the needs of their parents. The cohort study in the Hidden from View report<sup>59</sup> extends the analysis to those aged 20 and 21 showing that within this age group those who had caring responsibilities as a young person are more likely to be in professions such as personal service, sales or customer service occupations than their peers, and less likely to be in managerial, associate or skilled trade roles than their peers. In addition it was found that young carers are sometimes influenced by the skills gained through their experiences, for example, applying for work in the ‘caring professions’.

### **Older Carers Aged 65 and Over**

Responses to the NHS Survey of Carers in Households 2009/10 show that carers aged 65 years and over are more likely to be a sole carer (54% compared to 32%), more likely to live in the same household as the cared for person (59% compared to 47%) and are significantly more likely to care for 35 hours or more per week (40% compared to 26%). The latter is supported by evidence from the Census which shows that a similar proportion of carers aged

<sup>58</sup> NIACE (2013): Access and Inclusion, Young Adult Carers and Education and Training

<sup>59</sup> The Children’s Society (2013). Hidden from View: The Experiences of Young carers in England



65+ provide care for between 20 and 49 hours per week as younger age groups, but considerably more do so for 50 hours or more per week (37% compared to 16%).

A report by Age UK<sup>60</sup> based on the findings of listening events with older carers highlights some of the key specific challenges faced by this group, including:

- The impact on their health caused by the demands of caring often including heavy lifting. This is compounded as the older carer is often experiencing poor health or the effects of growing older themselves;
- Increased levels of stress often arising out of the need to provide personal care at the same time as taking sole responsibility for previously shared tasks (e.g. cleaning, maintaining the home and garden);
- Financial pressures exacerbated by the fact that the Carers Allowance is not paid post retirement;
- Social isolation caused by difficulty in leaving the house which can be compounded by their former friends discomfort with the condition of the cared for person. In this context many carers highlight the importance of day care and respite services.

A survey by the Princess Royal Trust for Carers<sup>61</sup> goes some way towards quantifying many of these issues, with key findings including:

- Carers aged 60–64 experience the most financial difficulty, often juggling work with caring responsibilities for more than one person.
- The majority of older carers report caring for 60 or more hours a week – particularly those carers aged 70 or over
- Two thirds of older carers have long term health problems or a disability themselves. Commonly reported conditions are arthritis and joint problems, back problems, heart disease, cancer and depression.
- One third of older carers reported having cancelled treatment or an operation they needed due to their caring responsibilities.
- Half of all older carers reported that their physical health had got worse in the last year and seven in ten said caring had had a negative impact on their physical health.
- More than four in ten older carers said their mental health had deteriorated over the last year.
- Over three quarters of carers ages 60–69 said caring had a negative impact on their mental health.
- Less than half of carers aged 70 and over who have to lift the person they care for do not feel they can do this safely and confidently.
- More than eight out of ten older carers have worries for the future, about what will happen to the person they care for if they can no longer care.
- More than one third do not get breaks away from caring, and a further third get a break only once every 2–3 months or less.

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<sup>60</sup> Age UK (2010): Invisible but Invaluable

<sup>61</sup> The Princess Royal Trust for Carers (2011): Always On Call, Always Concerned. A Survey of the Experiences of Older Carers

## Carers of People with Dementia

National research has found that there are around 800,000 people with dementia in the UK, of which an estimated two-thirds live in the community<sup>62</sup>. If this proportion were applied to Solihull's dementia prevalence<sup>63</sup> this would mean that there are around 2,100 individuals living with dementia in the community. An ageing population suggests that the number of Solihull dementia carers is likely to rise to about 2,800 by 2025.

It is recognised that carers of people with dementia face a unique set of challenges, primarily due to the degenerative nature of the condition. Research commissioned by the Carers Trust<sup>64</sup> notes that for carers of people with dementia there is no such thing as a 'typical' caring journey. Other research has found that the burden of care increases in the later stages of dementia<sup>65</sup>, which may be particularly true where the cared for person is subject to additional co-morbidities. The way in which the person with dementia's illness affects them will vary, as will carers' capacity to cope, both physical and emotionally. However, the findings from the Carers Trust research suggest that there are a number of critical points during the caring journey, which can be particularly difficult for the carer to manage and when support is most needed. The type of care provided and the impact on the carer (both emotional and physical) will vary across these critical points which include:

- When dementia is diagnosed (a particularly critical issue as only around 44% of people with the condition have a diagnosis, meaning that many people who are undiagnosed never receive appropriate treatments and care and by extension their carers will not receive appropriate support);
- When the carer takes on an 'active' caring role;
- When the capacity of the person with dementia declines;
- When the person with dementia loses their mobility;
- When the person with dementia has other health problems;
- When the carer has to cope with behaviour problems;
- When the carer's own circumstances change;
- When the person with dementia becomes incontinent;
- When decisions about residential care and end of life care have to be made.

Research shows people who care for someone with dementia are particularly prone to feelings of guilt, confusion, resentment, helplessness, grief and sadness<sup>66</sup>, with some of these emotional difficulties particularly acute where the cared for person is a partner or spouse<sup>67</sup>. These feelings can be exacerbated by the fact that the care for person can have difficulty in making decisions and display a range of challenging behaviours including repetitiveness and restlessness which can result in disrupted sleep patterns for the carer.

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<sup>62</sup> Alzheimer's Society (2013) Dementia 2013: The Hidden Voice of Loneliness

<sup>63</sup> Projecting Older Peoples Population (POPPI) estimate for 2015

<sup>64</sup> Newbronner, R. Chamberlain, R. et al (2013) A Road Less Rocky: Supporting Carers of People with Dementia, Carers Trust

<sup>65</sup> Georges, J Jansen, S. et al (2008), 'Alzheimer's disease in real life – the dementia carer's survey', International Journal of Geriatric Psychiatry

<sup>66</sup> Benbow, SM, Ong, YL, Black, S and Garner, J (2009), 'Narratives in a users' and carers' group: meanings and impact', International Psychogeriatrics, 21, 1, Feb,33–39.

<sup>67</sup> O'Shaughnessy, M, Lee, K and Lintern, T (2010), Changes in the couple relationship in dementia care: spouse carers' experiences', Dementia: The International Journal of Social Research and Practice



One particular study found that over one third of carers of people with dementia studied had been subject to abusive behaviour by the cared for person. Many dementia carers also report increasing social isolation as a resulting of worsening dementia<sup>68</sup>.

A survey of carers of people with dementia<sup>69</sup> found that 33% of those who are of working age said they consider themselves to have a disability or long-term health problem, with the percentage increasing to 47% among those aged 65+. When asked if their caring role affected their physical or mental health 40% of working age carers said 'Yes, a lot' and a further 46% said 'Yes, a little', with similar proportions among older carers.

## **Sandwich Carers**

Carers UK surveyed over 1,000 people who cared for at least one dependent child and an adult at the same time (sandwich carers or dual carers)<sup>70</sup>. Many of those surveyed said that they were struggling emotionally or financially, were having difficulty managing work and care and that their caring responsibilities were taking a toll on their own family life. Among the key findings of the survey were:

- Only 12% of sandwich carers felt they were juggling everything well, over four in 10 (42%) were struggling to cope or at breaking point.
- Three quarters (74%) said that caring for both children and older or disabled loved ones had a negative impact on their ability to earn.
- Over two thirds (69%) said they had seen a negative impact on their ability to afford household bills.
- Almost two thirds (63%) said that sandwich caring had taken a toll on their relationship with their spouse or partner. Seven in 10 (69%) had seen their friendships suffer.
- Over half of parents worried about the effect on their children of having to juggle childcare with caring for an older parent or disabled relative.
- Four in 10 feared they were letting down their ageing parents or disabled loved ones.
- Only half of sandwich carers surveyed were able to juggle work and care.
- A third were caring round the clock and the vast majority of these carers (85%) had been forced to give up work to care.
- Women were four times more likely than men to have given up work because of multiple caring responsibilities.
- A high proportion (79%) of carers who had seen their work affected attributed this to the stress of juggling everything together.
- One in five respondents (22%) who were managing to juggle work and care, said their jobs were negatively affected by caring as a result of tiredness, lateness and absence.
- Over three quarters of working carers (77%) said that their employer was aware of their caring responsibilities; but 23% had not mentioned their caring responsibilities at work.

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<sup>68</sup> Capus, J (2005), 'The Kingston Dementia Cafe: the benefits of establishing an Alzheimer cafe for carers and people with dementia'

<sup>69</sup> Newbronner, R. Chamberlain, R. et al (2013) A Road Less Rocky: Supporting Carers of People with Dementia, Carers Trust

<sup>70</sup> Carers UK (2012) Sandwich Caring: Combining Childcare with Caring for Older or Disabled Relatives

## Section 6: Best Practice and What Works Evidence

This section of the report highlights national guidance, best practice relating to Carers and carer interventions.

This section of the report presents evidence of what works in relation to carer pathways, engagement, support and interventions through a combination of best practice recommendations and available academic research.

### National Guidance

The National Institute for Health and Care Excellence (NICE) produce evidence-based Quality Standards for those commissioning and providing health and social care services. NICE Quality Standards offer explicit quality statements and associated quality measures that should be adopted by commissioners and implemented by providers as part of local policy and practice. Where possible, these quality statements should be incorporated by health and social care commissioners to formulate service specifications and contracts, ensuring delivery through contractual monitoring of key performance indicators.

Five Quality Standards have Quality Statements relevant to carers: QS2 Stroke, QS1 Dementia, QS13 End of Life, QS11 Alcohol Dependency & Harmful Alcohol Use and QS3 Venous Thromboembolism Prevention. These can be accessed through [The National Institute for Health and Care Excellence website](#).

### Best Practice Approaches and Recommendations

#### **Cares and Personalisation - Improving Outcomes<sup>71</sup>**

This report by the Department of Health reviews best practice, with key points as follows:

- Whole-family approaches are the starting point – recognising the interdependence that most of us have with those closest/most important to us.
- Wherever possible and to the greatest extent possible, carers' expertise is recognised and utilised in assessing, planning and reviewing support to the person they care for, and in determining and meeting their own support needs.
- Where it is not physically possible to work with people as a 'family', that interrelationship is still recognised, even where entirely separate assessments/plans etc are conducted.
- In whatever setting or circumstance carers seek help or advice, they are routinely asked what level of support they are both willing and able to provide to the person they care for.
- Carers are an integral part of the design, delivery and evaluation of every aspect of carers' support and services.

Early intervention and prevention

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<sup>71</sup> Department of Health (2010) "Carers and personalisation: improving outcomes". Accessed at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213806/dh\\_122383.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213806/dh_122383.pdf)

- Accurate, up-to-date and reliable information and advice is easily available from a broad range of sources to any member of the community who might require it to support them in their caring responsibilities and to help them make informed decisions.
- There is a programme of activity aimed at widening awareness and understanding of carers and improving responsiveness across the whole community, including services such as transport, leisure, education, housing, health, and local employers and businesses.
- Once carers are identified, there is a range of services and support that is available to all carers, regardless of their eligibility for, or use of other care and support services.

#### Self directed support processes

- There is an ongoing programme of carer awareness-raising throughout the council, NHS and partners, which is helping to ensure that the importance and value of carers is recognised at all levels and throughout organisations in the local community. The programme includes senior management, leaders and elected council members as well as people on front-line services.
- There is an active approach to identifying carers and their needs at an early stage.
- Carers' needs matter and are regarded as 'everyone's business'. Investment in carer-specific expertise and leadership helps to ensure this approach.
- Carers are routinely involved in the assessment of the person needing support to provide their expertise and knowledge and their views of what works what does not. Carers are always asked which, if any, aspects of caring they are happy to continue with or not.
- Carers are made aware of the opportunity to have an assessment in their own right, even where the person they care for does not wish to have a community care assessment.
- Carers' assessments put carers in control through self-directed approaches, with access to support or advocacy as required.
- Young carers can benefit from specialist (age appropriate) assessment.
- Approaches to assessment are co-ordinated and information resulting from separate assessments is brought together by care managers to help inform support planning and identify those carers providing high levels of support.
- Systems are in place to ensure that assessment can take place in a timely way.
- Assessments of carers look beyond the caring role to consider the carer's needs for employment, training and a life beyond caring.
- Risks to carers of sustaining their caring role are always considered when making decisions on eligibility for community care services.

#### Support planning

- Support planning takes into account the needs of both the person needing support and the carer so that there is an integrated approach that makes best use of resources and delivers effective outcomes for everyone involved.
- Where appropriate, services and support needed to sustain the caring role are included as part of the personal budget of the person requiring support.

- Support planning for carers includes problem solving, information and advice. These are available to carers regardless of eligible needs.
- No assumptions are made about the willingness or ability of carers to take on responsibilities of managing the money, employing staff, procuring support or services etc, and there is a range of good support options available to assist with this.
- Carers are given information and advice on the range of good support options available to assist them and have a choice as to the level of responsibility they wish to exercise.

#### Carers needs

- There are systems in place to review carers' needs and respond to changes, and to react to emergency situations.
- Carers' needs are routinely reviewed alongside the needs of the person they support, or more frequently if required, using an outcome-focused approach.
- Carers' needs are an important part of the review stage of the person they support.
- There are systems to assess demand and gaps in provision for carers. Information on the choices, spending patterns and outcomes of carers with personal budgets is collected to inform commissioning and improve provision.

#### **Commissioning for Carers: an Action Guide for Decision-Makers**

This report from the Association of Directors of Adult Social Services (ADASS) offers a care pathway for carer support that considers the four key personalisation strands taken from the Department of Health's 'Putting People First' and suggests specific service categories that allow carers to be included, informed and supported according to their choices. The pathway covers both carers with entitlements to a high level of statutory support and those with few or as yet undefined entitlements. The categories of support offered are:

- The universal offer of advice and information for all carers set out in Putting People First;
- Assessment, brokerage and advocacy to help people find their way through the system;
- Preventative and emergency support, currently the subject of a major funding stream.

Overarching all these categories of support the action guide recommends the need for capacity building and local infrastructure work which put caring at the heart of the community. This could include:

- Training agencies to be more carer-friendly and raise local awareness;
- Working with local employers to become more carer- and disability-friendly;
- Advocating on behalf of carers and helping carers' voices to be heard by decision-makers;
- Working with overlooked groups and communities.

## Commissioning for Carers<sup>72</sup>

The Royal College of General Practitioners guidance on Commissioning for Carers identifies two different broad approaches to programme design.

- Umbrella Approach: an overarching strategy that addresses the needs of all carers;
- Integrated Approach: addressing the needs of carers in every commissioning programme undertaken

The report suggests that there is no right answer to which approach should be adopted, with the decision should be based on what method fits the local situation.

	<b>Umbrella Approach</b>	<b>Integrated Approach</b>
Pros	Enables primary focus on the common aspects of carers experiences	Enables primary focus on the needs of those caring for people with specific conditions
	Facilitates joint commissioning with local authority	May improve integration of carer support as part of integrated care pathway design
	May enable a networked approach to service development and economies of scale	May facilitate involvement of people who are cared for in sharing their insights and concerns about those caring for them
Cons	May make it more difficult to integrate carer services within condition specific care pathways	May lead to fragmentation and duplication of carer support services and prevent economies of scale
<i>Source: Commissioning for Carers: Royal College of General Practitioners</i>		

The report goes on to highlight a range of local area best practice exemplars under the following headings:

- Identifying carers;
- Supporting professionals;
- Preventing hospitalisation and crisis;
- General practice;
- Pharmacy;
- Voluntary sector;
- Carer mental and physical wellbeing;
- Supporting carers to successfully juggle life and caring;
- Caring at the end of life.

## The Triangle of Care. Carers Included: A Guide to Best Practice for Dementia Care<sup>73</sup>

The Triangle of Care describes a therapeutic relationship between the person with dementia (patient), staff member and carer that promotes safety, supports communication and sustains wellbeing. The Triangle of Care model of carer inclusion and support has proved to

<sup>72</sup> Royal College of General Practice (2013), Commissioning for carers. Available at <http://www.rcgp.org.uk/clinical/clinical-resources/~media/Files/CIRC/Carers/RCGP-Commissioning-for-Carers-2013.ashx>

<sup>73</sup> The Princess Royal Trust for carers (2013), The Triangle of Care - Carers Included: A Best Practice Guide in Acute Mental Health Care available at <http://static.carers.org/files/caretriangle-web-5250.pdf>

be very successful in mental health services with over three quarters of mental health providers in England involved in the project and the model being adapted for use in Scotland and Wales.

Although the Triangle of Care was originally developed for use in mental health services, the standards outlined below have been found applicable in other care settings.

The rationale for each of these standards is explained, and examples of best practice highlighted. Planning to achieve an effective Triangle of Care is based on the recognition that the service needs to ensure each element is put in place to create and sustain the engagement required to achieve better outcomes. The six key standards state that:

1. Carers and the essential role they play are identified at first contact or as soon as possible thereafter.
  - Carers are identified and have their needs assessed along with the person with dementia.
  - Carers' views and knowledge are sought, shared, used and regularly updated as overall care plans to support treatment and care are developed.
2. Staff are 'carer aware' and trained in carer engagement strategies.
  - Staff need to be aware of and welcome the valuable contribution carers can make and be mindful of carers' own needs as well as the needs of people with dementia.
  - Staff need knowledge, training and support to become carer and dementia aware.
3. Policy and practice protocols regarding confidentiality and sharing information are in place.
  - To ensure proactive engagement carers need to be part of care planning and treatment and the service should have clear policies and mechanisms and ensure these are routinely used, including:
    - Guidelines on confidentiality and for sharing information – a three-way process between the person with dementia, carer and professional – which includes assessment of capacity and best interests decisions.
    - Protocols and approaches that facilitate information sharing.
    - Use of lasting power of attorney advance directives or plans.
4. Defined post(s) responsible for carers are in place.
  - Carers lead or champions for all wards and teams who are skilled and knowledgeable about dementia.
5. A carer introduction to the service and staff is available, with a relevant range of information across the care pathway.
  - An introductory letter from the team or ward explaining the nature of the service provided and who to contact.
  - An appointment with a named member of the team to discuss the carers' views and involvement.
  - Ward orientation/induction procedure and leaflet.
  - Carer information packs.

- Discharge planning and aftercare support.
6. A range of carer support services is available.
- Carer support.
  - Carer needs assessment.
  - Mechanisms for gathering feedback which are used to inform service improvement.

### **New Approaches to Supporting Carers' Health & Wellbeing<sup>74</sup>**

This evaluation of the National Carers' Strategy demonstrator sites programme reports on a programme in which the Department of Health supported 25 local partnerships to develop innovative services for carers.

The report makes the following recommendations:

- In all localities, efforts to bring local authorities, NHS organisations and voluntary sector organisations together to develop and deliver effective support for carers, in partnership, should be strengthened.
- Local carer support partnerships should involve a diverse range of carers in service development.
- In delivering support to a wide range of carers and reaching carers not already in touch with services, local partnerships should work flexibly, and sometimes on an ad hoc basis, to engage carers in specific target groups.
- Effective carer support at the local level should always include a varied portfolio of carer support services, which can be adapted to meet individual needs.
- Portfolios of carer support need to be agreed locally between local authorities, NHS organisations, voluntary sector organisations and other organisations where appropriate.
- Hospitals should routinely provide mechanisms to 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 where patients are likely to be accompanied by those who care for them.
- 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.
- 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 wellbeing and equipped to advise on how a carer can access a health and / or wellbeing check.
- All relevant organisations should regularly offer carer awareness training to their staff.

### **Making our health and care systems fit for an ageing population<sup>75</sup>**

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<sup>74</sup> Centre for International Research on Care, Labour & Equalities (2011), *New Approaches for Supporting Carers' Health and Wellbeing: Evidence from the National carers Strategy Demonstrator Sites Programme.*



The Kings Fund (2014) assessed evidence for types of interventions to make the care system appropriate for an ageing population. It stated that local leaders in health and social care, mental health, local government, and their voluntary sector partners should review the needs of carers for older people in terms of peer support, education, information and training, and respite, incorporating these into all health and wellbeing plans and mapping their own service provision against national strategies for carers. It also stated that carers should be involved in discharge planning.

### **Improving Support for Young Carers – Family Focused Approaches<sup>76</sup>**

This report by the Department for Education reviewed 15 Local Authorities who had received funding to test family focused models of working to improve outcomes for families at risk.

It was found that the support provided was particularly effective for families requiring high levels of support. Additionally the proportion of children undertaking inappropriate caring roles reduced from 50% to 30%, and the level of concern for the remaining 30% had dropped significantly. Only 7% were deemed to be providing a level of support which was significantly adversely affecting their lives. Larger proportions of young carers were attending school (average school attendance increased from 64% to 81%) and there was a reduction in the number of children identified with child protection risks between entry and exit.

Voluntary agencies were commissioned to deliver this support in two thirds of areas and the majority of models had moved away from respite care for the carers towards delivering support for the whole family. Examples of support provided included:

- Referring adults in family for additional support (eg substance misuse services);
- Parenting support;
- Emotional and financial support;
- Additional support for young carers transitioning to adult services;
- Engaging the wider family;
- Providing volunteer mentors;
- Engaging family in positive activities.

It was found that Common Assessment Frameworks for whole families helped practitioners to identify the support required for each family, with Team Around the Family (TAF) approaches also found to be useful.

### **There's nobody is there – no-one who can actually help? The challenges of estimating the number of young carers and knowing how to meet their needs<sup>77</sup>**

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<sup>75</sup> Oliver D, Foot C, Humphries R (2014). Kings Fund: "Making our health and care systems fit for an ageing population". Accessed at: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf).

<sup>76</sup> Department of Education (2011): Ronicle J, Kendall S "Improving Support for Young Carers – family focused approaches". Accessed at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/182291/DFE-RR084.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/182291/DFE-RR084.pdf)

<sup>77</sup> The Children's Society (2016). There's nobody is there – no-one who can actually help? The challenges of estimating the number of young carers and knowing how to meet their needs. Policy Briefing. Accessed at: [http://www.childrensociety.org.uk/sites/default/files/CFD094\\_YoungCarers\\_Report\\_Summary\\_V6\\_LOW%20RES%20SINGLE%20PAGES.pdf](http://www.childrensociety.org.uk/sites/default/files/CFD094_YoungCarers_Report_Summary_V6_LOW%20RES%20SINGLE%20PAGES.pdf)



A recent report by the Children's Society made the following recommendations for local authority strategic leads and commissioners:

- Local Safeguarding Children Boards (LSCBs) and Local Safeguarding Adult Boards (LSABs) should compare their audits of children and adults caseloads to help to identify young carers and ensure appropriate referrals.
- Health and Well-being Boards (HWBs) provide the opportunity for leaders in the health and care sectors to work jointly to improve health and well-being.
- Representatives from specialist young carer services should be included on LSCBs and HWBs as appropriate to ensure effective information sharing.
- Local authorities should audit what provision is available for those outside the age range of local young carers services.
- Service providers and commissioners need to ensure that information about local provision is well-promoted, kept up to date and is accessible
- Commissioners in local authorities could explore joint commissioning of services with adult and children's services or across a number of geographical locations to maximise resources.
- Funding organisations could provide creative opportunities to deliver support on a more long-term basis such as:
  - Longer contract time frames to allow young people and their families to have a professional they can trust and for young people to have someone who knows about their individual needs as well as their caring role.
  - Developing a peer mentoring system for young carers providing a regular, ongoing (and low cost) contact for a young person, and a development opportunity for the mentor.
  - Creating an 'innovation fund' for young carers services to try new approaches and improve knowledge transfer.

## Academic Research

A systematic review by Parker et al (2010)<sup>78</sup> looks at 23 reviews across all ages of Carers (including children and young adults). The findings are arranged by particular aspects caring and the lives of carers: physical health; mental health; burden, stress and strain; coping and coping skills; satisfaction, wellbeing and quality of life; ability and knowledge. Parker found that the best evidence was that education, training and information for carers (particularly when targeted at a particular parent group) improved knowledge and caring 'abilities'.

A systematic review by Victor (2009)<sup>79</sup> organises findings by type of intervention: Statutory carer assessment; Information services; Direct payment schemes; Support workers; Interventions focused upon carers' health; Carer support groups; Stress management, coping and counselling programmes; Befriending schemes; Education programmes for carers; Training for carers; Employment-related interventions; Carer breaks.

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<sup>78</sup> Parker, G., Arksey, H., & Harden, M. (2010). Meta-review of international evidence on interventions to support carers. York: Social Policy Research Unit, University of York.

<sup>79</sup> Victor, E. (2009). A Systematic Review of Interventions for Carers in the UK: Outcomes and Explanatory Evidence. London: The Princess Royal Trust for Carers. Accessed via: <http://www.scie-socialcareonline.org.uk/a-systematic-review-of-interventions-for-carers-in-the-uk-outcomes-and-explanatory-evidence/r/a11G000000182OilAI>

Victor notes that, of the studies reviewed, those employing qualitative research methods were more likely to report positive benefits from specific interventions than quantitative studies that often found no measurable impact on outcome measures. Qualitative work is therefore regarded as being helpful in identifying particular benefits, such as feeling recognised and valued, that can be missed in standardised quantitative outcome measurement.

Victor's systematic review includes a range of conclusions and recommendations and provides the basis for much of the evidence relating to specific carer interventions in the section below.

## Carer Interventions

### **Statutory Carer Assessments**

Victor suggests that statutory carer assessment can be very helpful to carers. It can be of practical benefit through linking carers into other direct support services. However, the evidence suggests that this only occurs for a proportion of carers, often less than half. Perhaps less intentionally but nonetheless importantly, assessment can also constitute a useful cathartic, emotional process. It can allow carers to express themselves, reflect upon their situation, receive recognition and validation from others and to feel supported.

The review found that many factors potentially influence the success or otherwise of assessment. The qualities and approach of the staff conducting the assessment were potentially very significant. Assessments may be more helpful if they are provided by staff who: have good interpersonal skills; provide active assistance; are skilled and knowledgeable in carer support; and who follow up actions and maintain contact. The centring of the assessment upon the individual carer, their preferences and expertise is also likely to be important. Following on from this, a broad approach which focuses specifically on the outcomes the carer wishes to achieve has shown particular promise. Carers may have individual preferences about the extent of the information they want prior to assessment and whether or not it is held in private, separately from the person receiving care. The subsequent availability and nature of resources to meet needs identified in assessment and follow up on these is also important.

The review concludes that:

- There is currently a focus amongst local authorities on meeting performance targets for the number of carer assessments achieved. This should be matched by a focus upon the quality of these assessments.
- Attention to staff training and approaches in this area is particularly important.
- The availability and adequacy of resources to meet needs identified in assessment has to be addressed.

### **Personal Budgets/Direct Payments**

Victor found weak evidence from one study that direct payment schemes can alleviate financial pressures, relieve stress and facilitate the provision of appropriate, effective support services for parent carers of disabled children.

A more recent evaluation of the personal health budget programme by the Department of Health (2012)<sup>80</sup> revealed some positive findings related to the health of carers who received personal health budgets:

- More likely to report better quality of life and perceived health compared to carers assisting an individual in the control group
- Generally reported lower instances of having their health affected by their caring role
- Carers seemed to be satisfied with the personal health budget process in terms of planning, the amount of budget and the amount of help offered when deciding what services or support to purchase from the personal health budget.

Overall, although these evaluations found improvements in carer's general health and wellbeing, the findings of these studies should be treated with caution due to the small sample sizes of carers. Personal health budgets have the potential to have a positive impact on the lives of carers; however a larger research study would be required before firm conclusions could be made.

A report by the Kings Fund (2014)<sup>81</sup> argues that Local authorities should ensure older people are offered the choice to take up personal health budgets, with many reporting a positive impact of these services. However, it notes that benefits are less clear for younger people with mental health or disabilities.

### **Telecare and Telehealth**

A Scotland Government report has considered the impact upon carers of providing Telecare to people with dementia, learning disabilities and others<sup>82</sup>. It indicated that nearly three quarters of carer respondents felt that telecare equipment had reduced the pressure on them by reducing stress levels; with only 4.3% feeling that their stress levels had increased.

Families and carers had greater peace of mind as they worried less (e.g. about falls and risks). The report suggested that people with learning disabilities could enjoy greater independence whilst people with dementia could remain living in the community for longer. Where stress levels had fallen, several respondents highlighted that caring nevertheless was still very demanding and stressful (especially if the client would not use the new equipment). There are three valuable outcomes here for carers: caring is sustained; people continue to live independently and fears for well-being and safety reduced. Feedback from carers suggests these are important outcomes.

The Kings Fund found that the evidence for telehealth services for people with long-term conditions is mixed, with the best evidence pointing to possible effectiveness of telecare services for older people with specific conditions such as cardiac failure, diabetes or chronic lung disease. Telecare has also been shown to provide reassurance to carers and relatives that could, in turn, have potential to reduce demands on health and social care.

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<sup>80</sup> Department of Health (2012). Forder J, Jones K, et al. Evaluation of the Personal Health Budget Pilot Programme

<sup>81</sup> Oliver D, Foot C, Humphries R (2014). Kings Fund: "Making our health and care systems fit for an ageing population". Accessed at: [http://www.kingsfund.org.uk/sites/files/kf/field/field\\_publication\\_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf](http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/making-health-care-systems-fit-ageing-population-oliver-foot-humphries-mar14.pdf).

<sup>82</sup> Newhaven Research (2011). The Telecare Development Programme in Scotland

## **Carers Breaks/Respite Care**

The Victor review found evidence that breaks offer carers a rest (emotionally and physically) and also allow carers to do things including catch up with everyday household tasks, social activities and sometimes employment. There was evidence that this type of intervention can be critical to the ability of some carers to continue caring.

However, the service may also constitute a first step on a fairly inevitable journey to stop caring for some carers. There is complexity in the influence of carer breaks upon carers' emotional well-being. They may offer relief, a sense of normality and freedom but also often lead to feelings of guilt and anxiety.

There was variation in preferences for different types of breaks service (for example, day care, short stay residential care or sitting services). There was some quite consistent evidence about factors which influenced satisfaction with and the potential benefits of breaks services. The nature and quality of the alternative care provided to the relative or friend of the carer was very important. This included its acceptability to the person receiving care, staff characteristics, the activities on offer and general environmental factors. The extent and timing of provision was also important to carers and tailoring and flexibility in services were valued.

The review concludes that:

- Carer breaks should continue to be a priority in carer service development.
- Those planning breaks services across a local area should consider whether they are offering an adequate supply and range of types of carer breaks.
- Those planning and running specific breaks services should consider, in particular, the flexibility of their provision and the nature and quality of the alternative care provided.
- It would also be useful for service providers to consider what they can do to address or ameliorate the sometimes difficult emotions experienced by carers using breaks services.

A more recent report for the Daily Stress and Health of Family Caregivers Study<sup>83</sup> found that getting regular breaks from providing care to a person with dementia can have a beneficial effect on a caregiver's health, while measured stress levels were reduced among carers attending an adult day care centre.

A report for the Princess Royal Trust for Carers and Crossroads Care (2011) states that investing in respite care results in savings resulting from reduced costs to health and social care: spending more on breaks, training, information, advice and emotional support for carers reduces overall spending on care by more than £1bn per annum, as a result of reductions in unwanted (re)admissions, delayed discharges and residential care stays.

## **Carer Support Groups**

The Victor review notes that whilst the outcome measurement evidence on carer support groups was generally weak in quality, it suggested that these may lead to a wide range of

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<sup>83</sup> The effects of adult day services on family caregivers' daily stress, affect, and health: outcomes from the Daily Stress and Health (DaSH) study (2014). Zarit, SH, Kim K, Femia EE, Almeida DM, Klein LC.

significant outcomes. These included: receipt of information and advice on a range of topics and issues; emotional support from other group members and through the development of confidence and a carer identity; social inclusion through meeting others, developing friendships and participating in social activities and outings; and sometimes facilitation of access to other services.

It was clear that the specific nature of individual support groups could be quite influential in terms of the outcomes achieved. In particular, the following could be significant, whether a group: was linked to a service; had more narrowly defined criteria for membership; or was led by a professional or run by peers.

The review concludes that:

- The evidence suggests it is worth supporting and researching carer support groups further. This is particularly the case given that these may offer a relatively inexpensive form of support as they can be delivered to several carers at a time and generally have relatively limited overhead costs.
- Given the potential significance of different types of support group, those organising and running groups should consider the aims, activities, membership, leadership and evaluation of individual groups carefully.
- Within local areas, it might be helpful to review the number and range of different groups available and to consider whether there are gaps in provision or whether some provision might benefit from changes.

## **Education and Training for Carers**

Victor notes that studies reported quite consistently that education and training programmes for carers can add to knowledge and skills as they are intended to. This was found for a range of types of education and skills training aimed at carers of people with various specific medical conditions. Improvements could also be fairly substantial in size. As well as building new knowledge and skills, it was reported as useful that these programmes sometimes validated existing knowledge amongst carers. In relation to training, however, there was some evidence that skills may not be maintained over time. There was some evidence that training could also have a beneficial impact upon emotional well-being including improved perceptions of the difficulties of caring and the carer's ability to manage.

Relevant contextual factors that could influence the outcomes of these interventions included: the topics covered; format of delivery; timing of delivery (the stage of caring participants were at); and the presence or not of the person receiving care. The delivery of education programmes in a face-to-face format but supported by written information appeared to be most useful. Provision of these interventions at earlier stages of the caring journey seemed to be beneficial, although further research would be needed to establish the extent of this. Particular aspects of training style noted as important included: the use of interaction; personalisation of the content; and the use of problem-solving approaches with others.

The review concludes that:

- Education and training should continue to be provided to fulfil specific carer needs for knowledge and skills development.

- Those developing and running these types of intervention should consider structural aspects of the intervention likely to influence its success, particularly the timing and the format of delivery.

## Appendix 1: Future Care Needs

In order to set the context for the future burden of care, much of will be met by unpaid carers, projections from PANSI and POPPI set out the prevalence of certain conditions in Solihull's adult and older peoples population that are likely to result in the individual requiring care. This achieved by applying national prevalence rates to the existing and future age group population of Solihull.

### Learning Disability

Learning Disability is relatively common affecting 2% of the national population which would equate to approximately 4,200 people of all ages in Solihull, while severe learning disabilities are less common affecting around 0.4% of the population (approximately 840 people in Solihull).

Increases in the number of people with a Learning Disability are a result of a range of factors, including<sup>84</sup>:

- Decreasing mortality among people with learning disabilities, especially in older age ranges and among children with severe and complex needs;
- The impact of changes in fertility over the past two decades in the general population;
- The ageing of the 'baby boomers', among whom there appears to be an increased incidence of learning disabilities.

The proportion of adult Solihull residents aged 18 and over with a Learning Disability is projected to increase by around 5% between 2015 and 2025 (+175 individuals), with increases greater among older age groups (+20% among 55-64 year olds and +17% among 65+).

	<b>Solihull Learning Disability Population Aged 18+</b>			
	2015	2020	2025	2030
Aged 18-24	422	381	377	413
Aged 25-34	575	613	608	578
Aged 35-44	614	608	652	689
Aged 45-54	743	693	628	628
Aged 55-64	572	646	686	643
Aged 65-74	501	508	493	559
Aged 75-84	284	328	389	396
Aged 85+	124	148	177	220
Total 18+ LD Population	3,835	3,925	4,010	4,126
Change (from 2015)		+90	+175	+291
		+2%	+5%	+8%

<sup>84</sup> Solihull MBC (2012); Joint Strategic Needs Assessment

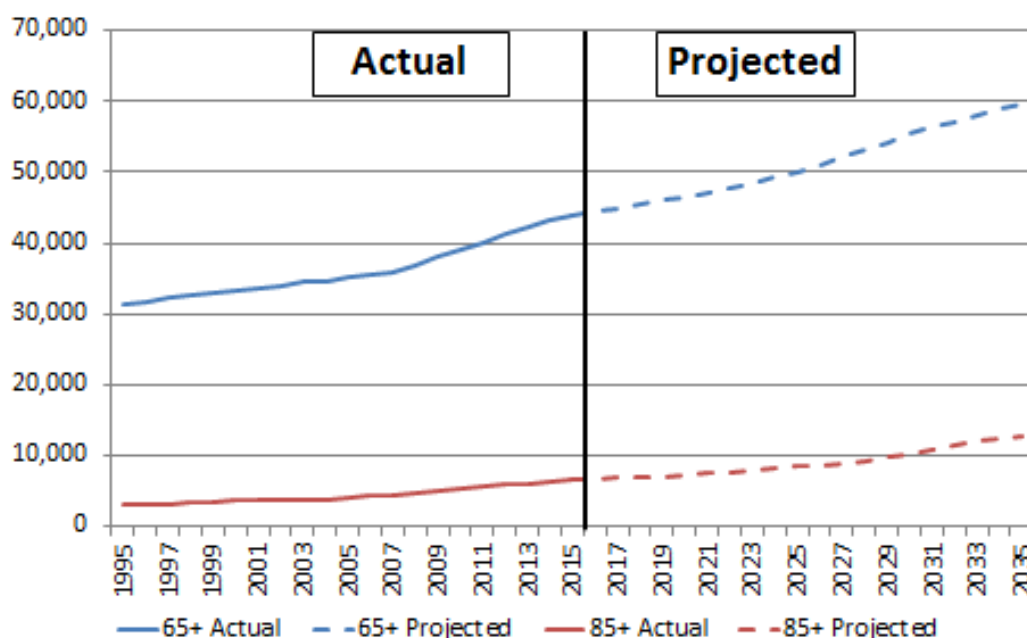


Research by Hatton and Emerson<sup>85</sup> points out that increasing numbers of people with a Learning Disability will increase demand on adult social care services, depending on policy decisions around eligibility for services. However, assuming only those with a moderate or severe learning difficulty, who represent just an estimated 20% of all those with a learning disability, are eligible for formal social care the burden will continue to fall heavily on family members and other carers.

## Older People

ONS population estimates suggest that the number of older people aged 65+ in Solihull will increase by 14% between 2015 and 2025, with the increase even greater among the very oldest (the numbers aged 85+ projected to increase by 30%, 1,900 individuals).

### Solihull Older People Population



Source: ONS Mid Year Population Estimates and Projections

An ageing population will result in more people living with a long term health condition. This is because nationally the successful management and treatment of long term conditions such as heart disease is resulting at overall life expectancy increasing faster than healthy life expectancy.

On this basis it is clear that the ageing population will have a significant impact on the burden of care for both social care services and unpaid carers. This will include increasing numbers of older people who are frail and unable to undertake domestic, self care and mobility tasks, with a resulting loss of independence.

<sup>85</sup> E. Emerson & C. Hatton, Centre for Disability Research (2008): Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England



It is estimated that around 18,300 individuals in Solihull aged 65+ are unable to do at least one domestic task<sup>86</sup>, 67% of which will be aged 75+ (12,200 individuals) and 28% aged 85+ (5,100 individuals). The estimated 18,300 individuals in the borough unable to manage at least one domestic task represent 42% of the 65+ population (26% of 65-74 year olds, 50% of 75-84 year olds, 79% of 85+ population).

The number of people who are unable to manage at least one domestic task is projected to increase by 10% between 2015 and 2020 and by 37% by 2030, by which time it is estimated that over 25,000 individuals will be unable to do so.

	<b>Solihull 65+ Population Unable to Manage at Least One Domestic Task</b>			
	<b>2015</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>
Age 65-74 Years	6,097	6,245	5,970	6,783
Age 75-84 Years	7,098	8,012	9,447	9,726
Age 85+	5,090	5,922	6,972	8,554
Total 65+	18,285	20,179	22,389	25,063
Total Change (from 2015)		+1,894	+4,104	+6,778
		+10%	+22%	+37%

*Source: POPPI*

It is estimated that around 15,000 individuals in Solihull aged 65+ are unable to do at least one self care activity<sup>87</sup>, 66% of which will be aged 75+ (9,900 individuals) and 29% aged 85+ (4,400 individuals). The estimated 15,000 individuals in the borough unable to manage at least one self care activity represent 34% of the 65+ population (22% of 65-74 year olds, 39% of 75-84 year olds, 68% of 85+ population).

The number of people who are unable to manage at least one self care activity is projected to increase by 10% between 2015 and 2020 and by 37% by 2030, by which time it is estimated that over 20,500 individuals will be unable to do so.

	<b>Solihull 65+ Population Unable to Manage at Least One Self Care Activity</b>			
	<b>2015</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>
Age 65-74 Years	5,104	5,193	4,994	5,674
Age 75-84 Years	5,555	6,269	7,392	7,629
Age 85+	4,355	5,054	5,929	7,253
Total 65+	15,014	16,516	18,315	20,556
Total Change (from 2015)		+1,502	+3,301	+5,542
		+10%	+22%	+37%

*Source: POPPI*

<sup>86</sup> Tasks include: household shopping, wash and dry dishes, clean windows inside, jobs involving climbing, use a vacuum cleaner to clean floors, wash clothing by hand, open screw tops, deal with personal affairs, do practical activities

<sup>87</sup> Activities include: bathe, shower or wash all over, dress and undress, wash their face and hands, feed, cut their toenails, take medicines

There are an estimated 8,300 individuals aged 65+ in Solihull who are unable to do at least one mobility activity<sup>88</sup>, 70% of which will be aged 75+ (5,800 individuals) and 36% aged 85+ (3,000 individuals). The estimated 8,300 individuals in the borough unable to manage at least one mobility task represents nearly 19% of the 65+ population (11% of 65-74 year olds, 20% of 75-84 year olds, 46% of 85+ population).

The number of people who are unable to manage at least one mobility activity is projected to increase by 11% between 2015 and 2020 and by 40% by 2030, by which time it is estimated that over 11,600 individuals will be unable to do so.

	<b>Solihull 65+ Population Unable to Manage at Least One Mobility Activity</b>			
	<b>2015</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>
Age 65-74 Years	2,469	2,548	2,426	2,745
Age 75-84 Years	2,880	3,241	3,825	3,976
Age 85+	2,955	3,430	4,025	4,925
Total 65+	8,304	9,219	10,276	11,646
Total Change (from 2015)		+915	+1,972	+3,342
		+11%	+24%	+40%

*Source: POPPI*

Continence is another significant factor in loss of independence among older people and is one of the practical issues that can distress carers and place a significant strain on the relationship between the carer and the cared for person<sup>89</sup>. It is estimated that the number of people aged 65+ who have a bladder problem will increase by around 19% between 2015 and 2025 (from 8,700 to 10,400).

## **Dementia**

Research by the Alzheimer's Research Trust 2010<sup>90</sup> suggests there are about 820,000 patients in the UK with dementia representing 1.3% of the UK population. This is an underestimate of the actual prevalence of dementia in the population because of a range of barriers to diagnosis, including:

- fear of the disease in the patient or family;
- inability to separate dementia symptoms from normal ageing process;
- GPs' lack of training and confidence in diagnosing dementia;
- unclear roles or inconsistent approaches of specialist services such as Memory Services;
- variation and inconsistency in the available diagnostic tools.

Given the association between dementia and an ageing population, the number of people living with dementia is projected to increase sharply between 2015 and 2030. It is estimated

<sup>88</sup> Activities include: going out of doors & walking down the road; getting up & down stairs; getting around the house on the level; getting to the toilet; getting in and out of bed.

<sup>89</sup> Cheffings, J. (2003) Report of the Princess Royal Trust for Carers. London: Princess Royal Trust for Carers.

<sup>90</sup> Alzheimer's Research Trust (2010) Dementia 2010: The Economic Burden of Dementia and Associated Research Funding in the UK

that, as at 2015, there were around 3,200 Solihull residents aged 65 and over with dementia, 86% of which will be aged 75+ (2,760 individuals) and 48% of which will be 85+ (1,540 individuals). The estimated 3,200 individuals in the borough with dementia represent 7% of the existing 65+ population (2% of 65-74 year olds, 9% of 75-84 year olds, 24% of 85+ population).

The number of people aged 65+ with dementia is projected to increase by 16% between 2015 and 2020 and by 55% by 2030, by which time it is estimated that around 4,950 individuals will have the condition. The specific challenges for carers of individuals with dementia are discussed later in this report, although it is worth noting that increases of this magnitude of the number of people living with dementia mean that increasing numbers of Solihull carers will require specialised support in the future.

	<b>Solihull 65+ Dementia Population</b>			
	<b>2015</b>	<b>2020</b>	<b>2025</b>	<b>2030</b>
Age 65-74 Years	444	469	440	494
Age 75-84 Years	1,219	1,367	1,616	1,723
Age 85+	1,539	1,882	2,184	2,732
Total 65+	3,202	3,719	4,239	4,948
Total Change (from 2015)		+517	+1,037	+1,746
		+16%	+32%	+55%
<i>Source: POPPI</i>				

## Appendix 2: Glossary

**ASC:** Adult Social Care services including commissioner and provider services.

**ADASS:** The Association of Directors of Adult Social Services (ADASS) represents all the directors of adult social services in England as well as senior managers who report to them.

**Adult Carer:** An adult carer is anyone 18+ who spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.

**ASCOF:** The Adult Social Care Outcomes Framework (ASCOF) is used both locally and nationally to set priorities for care and support, measure progress and strengthen transparency and accountability.

**CCG:** Clinical Commissioning Groups are groups of GP Practices, working with other healthcare professionals and in partnership with local communities and Local Authorities are responsible for commissioning the majority of NHS services for patients within their local communities. They have a duty to work with Local Authorities in relation to health and adult social care, early years services, public health.

**Census:** The Census for England & Wales takes place every ten years with the latest being conducted by the ONS in March 2011. The results are published and disseminated by the ONS.

**Direct Payments:** These are cash payments made to a service user or carer in lieu of directly provided or commissioned services (following an assessment of their needs). The direct payment can be for all or part of a persons assessed services. The service user can then use the direct payment to purchase services to meet their needs.

**DoH:** The Department of Health (DoH) is a ministerial department, supported by 23 agencies and national bodies. The department helps people to live better for longer and leads, shapes and funds health and care in England, ensuring people have the support, care and treatment they need, with the compassion, respect and dignity they deserve.

**LA:** A local authority is an administrative body in local government.

**NASCIS:** The National Adult Social Care Intelligence Service is a single national resource of social care information for England. The website has a collection of data, tools and resources designed to meet the needs of service planners, managers, researchers and policy makers and others.

**ONS:** Office for National Statistics the executive office of the UK Statistics Authority, responsible for collection and publication of statistics related to the economy, population and society of the UK.

**PANSI:** Projecting Adult Needs and Service Information a programme designed to help explore the possible impact that demography and certain conditions may have on populations aged 18 to 64. Developed by the Institute of Public Care for use by local authority planners and commissioners of social care provision in England, together with providers.

**POPPI:** Projecting Older People Population Information a programme designed to help explore the possible impact that demography and certain conditions may have on populations aged 65 and over. Developed by the Institute of Public Care for use by local authority planners and commissioners of social care provision in England, together with providers.

**Prevalence:** is the total number of cases of a disease in a given population at a specific time.

**RCGPs:** The Royal College of General Practitioners is the professional membership body and guardian of standards for family doctors in the UK, working to promote excellence in primary healthcare.

**Respite:** Carers trust define respite as 'taking a break'. See <http://www.carers.org/help-directory/respice-care> for types of respite.

**SALT:** The Short and Long Term Services data collection tracks the client journey through the adult social care system in England. It also reports on the Primary Support Reason (this describes why the individual requires social care support).

**SMBC:** Solihull Metropolitan Borough Council

**Systematic review:** Systematic reviews focus on peer-reviewed publications about a specific health problem and use rigorous, standardized methods for selecting and assessing articles.

**Young Carer:** The term young carer should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances.

**Young Adult Carer:** Young adult carers are those people that bridge the young carer and young adult carer cohorts and include those with caring responsibilities as an adolescent who are transitioning into adulthood. Young adult carers are usually categorised as being aged 16-24 years.