Working in partnership to deliver better outcomes for carers in the Royal Borough of Windsor & Maidenhead

Evidence Report
April 2014
Report structure

**Background**
- The essential roles carers play in health and social care
- The national and local policy context
- How the local council and NHS plan to meet the needs of carers through a new joint carers’ strategy
- Why a robust evidence base is being developed

**Review of evidence to date**
- Details of existing RBWM quantitative evidence and resources on carers
- Key findings from this initial review and how it has influenced the broader evidence base development

**The demand for care**
- Why the demand for care is growing
- The makeup of the population in RBWM
- The health and levels of deprivation in the local population
- Adults and children receiving statutory support
- How many people are accessing disability benefits

**The availability, makeup and experiences of carers and the impacts of caring**
- Who the local carers are, based on national datasets
- The health and economic impacts local carers experience
- How many people are accessing carers’ benefits
- Information on young carers and parent carers
- Experiences of carers as reported in national surveys

**Carers’ assessments and carers known to local services**
- Information on assessments and self-directed support
- The makeup of carers who have had an assessment
- Young carers and parent carers receiving support
- Comparisons between national and local data on carers to identify ‘hidden carer’ groups

**Key findings**
- Key findings to inform the development of the new joint carers’ strategy in RBWM
- Key findings to help prepare for the changes in the Care Bill and Children and Families Act
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1. Background

This section sets out
- The essential roles carers play in the health and social care system
- The national and local policy context for improving support for carers
- How the local council and NHS plan to meet the needs of carers through a new joint carers’ strategy
- Why a robust evidence base is being developed and what it entails

1.1 Introduction

The Royal Borough of Windsor & Maidenhead (RBWM), Windsor, Ascot and Maidenhead Clinical Commissioning Group (WAM CCG) and Bracknell and Ascot Clinical Commissioning Group (BAA CCG) are working together with Carers UK to develop a robust quantitative evidence base on carers that – combined with qualitative evidence already being compiled by RBWM and WAM CCG – will underpin the development of a new joint council and health carers’ strategy, and will demonstrate the impact that supporting carers can have on health outcomes for the carer and for the person they care for.

RBWM and local NHS partners are operating in an environment of reducing resources and increasing demand for care, and therefore want to ensure their approach to service planning and delivery leads to more effective, targeted health and social care services that have a broader reach and are tailored to the specific support needs of carers in RBWM, thus delivering better value return on investment.

1.2 Integral role of carers in the health and social care system

In the context of change and reducing resources, it is more essential than ever that commissioners and service providers across health and social care understand and support carers effectively. This requires them to recognise and understand the vital, distinct but interconnected roles carers play within the health and social care system, including:

- Carers as providers of care and support to those with health and social care needs
- Carers as partners in the management and treatment of health and social care needs
- Carers as a group with statutory rights and support needs
- Carers as a population with disproportionately high health and support needs

Due to the multiple roles that carers play, they impact on and are impacted by almost all health and social care services. Research has shown that carers save the state billions of pounds each year by providing much needed care to help sustain people in their own homes.\(^1\) Opportunities to identify, engage, partner with and support carers should be mainstreamed across all activities and pathways within health and

\(^1\) Valuing Carers (Carers UK, 2011)
social care, including strategy and policy development, service planning and service delivery.

1.3 National and local drivers for improving support for carers

1.3.1 Changing health and social care system
The health and social care landscape in England is going through a period of major change. In 2012, the Health and Social Care Act and the draft Care and Support Bill proposed the most dramatic changes to health and social care in the last sixty years, including an extensive reorganisation of the structures and governance of the NHS and widespread reform of social care law in England. These changes come alongside the implementation of the Welfare Reform Act which marks a radical shakeup of the benefits system and financial support for disabled people and their families.

1.3.2 Care Bill and Children and Families Act
The Care Bill currently going through Parliament presents massive changes to health and social care and will consolidate over 30 pieces of statute and numerous pieces of guidance, regulations and directions.

The legislation includes significant and welcome measures to improve the rights of adults caring for adults, including:

- New rights to assessment meaning that carers should find it easier to have their needs for support considered
- A national eligibility threshold bringing greater clarity around entitlement for carers and for those they care for
- Recommendations for a cap on long-term care with the potential to make paying for care more transparent
- A duty on local authorities to promote the wellbeing of carers
- Duties to provide information and advice and preventative services with the potential to get crucial advice to families at an earlier stage
- Important changes enabling care packages to be more easily transferred from one local authority to another
- Measures to ease the transition between children’s and adults services

The Children and Families Act – which received royal assent in March 2014 – will help to improve services for young carers and parent carers by:

- Extending the right to an assessment of support needs to all young carers under the age of 18 – regardless of who they care for or for how long
- Supporting local authorities to combine the assessment of a young carer with an assessment of the person they care for – providing a co-ordinated and rounded package of support for the whole family
- Simplifying the law relating to young carers – making their rights and duties clearer to both young people and professionals
- Consolidating and streamlining parent carers’ rights to assessment and support

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2 [http://services.parliament.uk/bills/2013-14/care.html](http://services.parliament.uk/bills/2013-14/care.html)
1.3.3 Local policy context
RBWM, WAM CCG and BAA CCG have recently worked together, in consultation with residents, to develop the Joint Health and Wellbeing Strategy (JHWS), which aims to improve local health and wellbeing outcomes. This identified three overarching themes for more focussed attention:
- Supporting a healthy population
- Prevention and early intervention
- Enabling residents to maximise their capabilities and life chances

Supporting carers in their caring role is a key area for action under these themes and RBWM, WAM CCG and BAA CCG are now working with carers and voluntary sector partners to develop a new carers’ strategy and action plan, to ensure carers of all ages are better supported and able to have a life outside of caring (see 1.4 Developing a new joint carers’ strategy).

RBWM has recently transformed social care service delivery in line with the personalisation agenda. My Care, My Choice is their new approach to social care – enabling people to choose and manage their own care through ‘self-directed support’. For unpaid carers, this means being part of the discussion about support for the person they care for, and not having to take on all the responsibility for their care, so that they can have a life of their own and are free to make choices about their own support needs.

1.3.4 Carers Support Commissioning Strategy
This 2004 strategy was reviewed in December 2006, and sets out how the statutory and voluntary sector will work together with carers and carers’ groups to develop and deliver services for adult carers in RBWM. It is the result of extensive consultation with the carers’ partnership board and was agreed, at the time, between RBWM and Berkshire East PCT.

The strategy identifies and discusses eleven components for an effective carers’ strategy including better information and signposting, the right to a carer’s assessment, and breaks from caring.

1.3.5 Multi-agency young carer strategy
A separate interagency strategy for supporting young carers was developed in 2006, following the establishment of an RBWM Young Carers Steering Group in 2004. The strategy aims to join up all the agencies that could make a positive impact on the lives of young carers, and to encourage them to take proactive steps to identify young carers and help them to access support.

The strategy includes evidence on young carers based on 2001 Census data and followed extensive consultation and mapping of existing provision, with recommendations from external specialists. It adopts a whole family approach to identifying, assessing and supporting the needs of young carers and lists strategic objectives to achieve this. The strategy also describes in detail how it will ensure its outcomes are measured.
1.4 Developing a new joint carers’ strategy

RBWM, WAM CCG and BAA CCG are keen to ensure that local priorities for carers are built into their new joint carers’ strategy, and that relevant elements of the refreshed national carers’ strategy\(^4\) are adopted.

This will align with the prevention agenda by focusing on identifying and providing low-level support to more carers early in their caring role, particularly ‘hidden carers’ who are not currently in touch with services. It will be backed up by a robust evidence base to ensure resources are targeted and allocated on the basis of need, so that carers who are most at risk of experiencing negative health and wellbeing outcomes as a consequence of taking on a caring role are better supported.

The overarching aim of the new strategy is to devise and deliver an effective, evidence-based and outcomes-driven approach to the strategic planning, commissioning and contracting of services for carers. It must meet the demands of the Care Bill and address the wider strategic priorities of health and social care delivery in Windsor and Maidenhead within the resources available. It will be delivered in partnership with Children’s services and be compliant with the young carers’ and parent carers’ aspects of the Children and Families Act.

1.5 Building a robust evidence base

RBWM, WAM CCG and BAA CCG held two workshop sessions with carers in December 2013 and have had 84 responses (as of January 2014) to an online survey that will provide qualitative evidence for the new strategy. Early analysis of the responses shows that high priorities for carers include having access to more information, respite, emergency support and support from their GP.

To support delivery of a robust joint carers’ strategy and action plan, and to align with the requirements of the Care Bill and Children and Families Act, Carers UK has undertaken a range of quantitative activities and analysis, including:

- A review of existing quantitative evidence and resources on carers in RBWM
- An analysis of the demand for care in RBWM based on the makeup, health and levels of deprivation in the local population
- An analysis of the availability, makeup and experiences of carers in RBWM including the impacts they experience on their health and economic activity
- A breakdown of the makeup of carers known to services in RBWM, drawing comparisons with national data to identify ‘hidden carer’ groups
- A review of the performance of carers’ services including the volume of carers’ assessments and self-directed support
- Supplementation of evidence base with external evidence and Carers UK Research library

This report sets out the evidence as described above, including the key findings which will inform the development of the new carers’ strategy and help prepare for the Care Bill and Children and Families Act.

\(^4\) Recognised, valued and supported: Next steps for the Carers Strategy (HM Government, 2010)
2. Review of evidence collected to date

This section sets out
- Details of existing RBWM quantitative evidence and resources on carers
- Key findings from this initial review and how it has influenced the broader evidence base development

2.1 Existing quantitative evidence base

2.1.1 Joint Strategic Needs Assessment (JSNA)
The local JSNA includes a section on carers (including young carers) as a vulnerable group. This includes definitions of ‘carer’ and ‘young carer’ and national evidence on carers and caring from the 2011 Census and Carers UK.

It provides some local evidence on carer numbers and the intensity of the caring role, based on those people living in households at the time of the 2011 Census.

It also identifies national and local ‘best practice’ strategies including the national carers’ strategy and the new Care Bill. It discusses the refresh of the Carers’ Strategy that is underway in RBWM and how this will be an integrated health and social care strategy that will cover all carers.

The section concludes by exploring what the current information on carers tells us:
- Access to information and advice is important to carers and needs to be considered in the strategy development
- The risks of health inequalities for carers because of their caring role is higher than the comparable population, so early intervention to prevent a crisis for the carer is essential
- The number of carers’ assessments taking place seems to be lower than expected, this will be scoped out as a part of the strategy planning
- Use of self-directed support for carers will be a part of this process
- With changes to welfare reforms, support for working carers is another area of development

2.1.2 A Strategy for Adult Care Services 2008-2020
This strategy provides a framework for the commissioning of adult social care services through to 2020 and beyond. Section 8 is a market analysis covering the available supply of care provision and support, and the demand placed on this by the needs of the population. Carers are featured throughout, and are analysed in more detail in section 8.12.

Section 8.12 reports key facts about adult and young carers from Carers UK and the Census, and analysis of local demand based on social care data. The latest social care data used is from 2007 and the Census data is from 2001. It reports that there are 11,500 carers in RBWM, including 1,700 providing more than 50 hours of care per week; it identifies 331 young carers and recognises this is likely to be an underestimate. The section also uses statistics published by Carers UK in 2007 to give some key facts about carers and employment.
2.1.3 Update on the Carers Survey 2012-13
RBWM has produced a short report detailing the findings of the national Personal Social Services User Experience Survey of Carers 2012-13. This report focusses in detail on the results of the survey which populate measures in the Adult Social Care Outcomes Framework (ASCOF), including analysis of RBWM’s performance against comparator local authorities based on the Chartered Institute of Public Finance and Accountancy (CIPFA) comparator group.

The report concludes that there is some room for improvement when RBWM’s results are considered against their comparators and the national average.

2.1.4 Adult Social Care Framework Results 2012-13
This report runs through RBWM’s results in the ASCOF and uses column charts to compare local performance against the CIPFA comparator group and England average.

There are four indicators that draw data from the National Carers’ Survey:
- 1D: Carer reported quality of life
- 3B: Overall satisfaction of carers with social services
- 3C: The proportion of carers who report they have been included or consulted in discussions about the person they care for
- 3D: The proportion of people who use services and carers who find it easy to find information about services

Indicators from the National Carers’ Survey are included for the first time in 2013/14 and will be updated biennially. These have been analysed in more detail in another paper (see 2.1.3 Update on the Carers Survey 2012-13).

2.2 Key findings and next steps

- The quantitative evidence base that exists on carers in RBWM is limited.
- There is no up-to-date analysis of the makeup of carers, or the impacts they face because of their caring role. This report will use the latest information available and analyse this in detail.
- Evidence on the experiences of carers who use services is available based on findings of the National Carers’ Survey and the Adult Social Care Outcomes Framework, and this will be analysed in further detail in this report.
- There is little quantitative evidence published on the makeup and needs of carers known to services in RBWM. This report will break this down in detail using the latest data available from statutory and voluntary services, as well as mapping the location of all carers against those known to services to help target support more effectively.
- The local JSNA provides limited local evidence on carers in RBWM. This report will provide a detailed needs analysis of carers in RBWM that could be incorporated into the local JSNA going forward.
- There is little quantitative evidence published on young carers and parent carers in RBWM. This report will analyse data on young carers and parent carers based on the latest evidence and estimates available.
3. The demand for care

This section sets out evidence to help us understand
- Why the demand for care is growing
- The makeup of the population in RBWM
- The health and levels of deprivation in the local population
- The number of adults and children receiving statutory support
- How many people are accessing disability benefits

3.1 Introduction

The UK population is growing rapidly, and the older population (aged 65 and over) in particular is growing faster than the younger adult population. Healthy life expectancy is also increasing, but not as fast as life expectancy, so more people are living into their old age with long-term clinical conditions that need to be managed.\(^5\)

The result of this is an increase in the demand for health and social care support. This increased demand – made worse by reductions to resources available to local authorities – has made the current system of social care provision unsustainable.\(^6\)

Central government has shifted some powers to local government and local communities to allow them to decide what will work best for their local populations. Local government has been given more power in health, and the statutory care bodies are required to set shared priorities and strategies across social care, the NHS and public health. Supporting carers is an issue which cuts across the whole health and social care system.

Local authorities have been raising their eligibility thresholds and many only support people with ‘substantial’ needs. Responsibility for care has been gradually transferred to individuals, their families or local communities; with the aim that they maintain maximum independence and control over their own lives. As more people spend their last years of life at home, so the demand for care in home settings increases.

The burden of support falls primarily on unpaid carers. Carers are the largest source of care and support in each area of the UK; however, the impacts on carers of providing this support are not always recognised or accounted for.

\(^5\) The UK Care Economy: Improving outcomes for carers (Carers UK and Cass Business School, 2012)

\(^6\) Fairer Funding for All (Dilnot Commission on Funding of Care and Support, July 2011)
This section provides information about the local demand for care based on the makeup and general health of the population, and numbers receiving statutory support and disability benefits. The following section will look in more detail at the availability and makeup of carers.

3.2 Population profile

There are 145,800 people living in RBWM based on the latest population estimates, of which 17.3% (25,200) are aged 65 and over. 49.3% of the population are male and 50.7% are female.

Between 2011 and 2021, the overall population is projected to grow by 11.2% to 161,300. The older people population (aged 65 and over) is projected to grow by 19.3% to 29,000.

Figure 1 below shows the population in each ward by broad age groups. Eton Wick is the least populated ward with 1.6% of the population (2,260 people) and Oldfield is the most populated with 6.3% of the population (9,141 people). Clewer North has the highest number of people aged 65 and over (1,576) and Eton and Castle has the fewest (232).

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7 Mid-2012 Population Estimates (ONS, 2013)
8 Census (2011)
9 Sub regional – population estimates and projections (ONS, 2013)
There are 58,349 households in RBWM including 37,618 families (64.5%) and 16,554 one person households (28.4%). Table 1 below shows that 3 in 10 (30.1%) people aged 65 and over are living alone. This ranges from just over one fifth (22.6%) of the older people in Ascot and Cheapside to just over half (51.4%) of the older people in Castle Without. The six wards with the highest number of older people living alone and the highest proportion of older people living alone have been highlighted in the table.

Table 1

<table>
<thead>
<tr>
<th>Area</th>
<th>All residents in households: Aged 65+</th>
<th>One person household: Aged 65+</th>
<th>% aged 65+ living alone</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ascot and Cheapside</td>
<td>837</td>
<td>189</td>
<td>22.6%</td>
</tr>
<tr>
<td>Belmont</td>
<td>1,000</td>
<td>344</td>
<td>34.4%</td>
</tr>
<tr>
<td>Bisham and Cookham</td>
<td>1,443</td>
<td>350</td>
<td>24.3%</td>
</tr>
<tr>
<td>Boyn Hill</td>
<td>1,116</td>
<td>283</td>
<td>25.4%</td>
</tr>
<tr>
<td>Bray</td>
<td>1,281</td>
<td>316</td>
<td>24.7%</td>
</tr>
<tr>
<td>Castle Without</td>
<td>882</td>
<td>453</td>
<td>51.4%</td>
</tr>
<tr>
<td>Clewer East</td>
<td>756</td>
<td>300</td>
<td>39.7%</td>
</tr>
<tr>
<td>Clewer North</td>
<td>1,505</td>
<td>441</td>
<td>29.3%</td>
</tr>
<tr>
<td>Clewer South</td>
<td>792</td>
<td>303</td>
<td>38.3%</td>
</tr>
<tr>
<td>Cox Green</td>
<td>1,115</td>
<td>257</td>
<td>23.0%</td>
</tr>
<tr>
<td>Datchet</td>
<td>683</td>
<td>229</td>
<td>33.5%</td>
</tr>
<tr>
<td>Eton and Castle</td>
<td>221</td>
<td>84</td>
<td>38.0%</td>
</tr>
<tr>
<td>Eton Wick</td>
<td>409</td>
<td>159</td>
<td>38.9%</td>
</tr>
<tr>
<td>Furze Platt</td>
<td>1,274</td>
<td>368</td>
<td>28.9%</td>
</tr>
<tr>
<td>Horton and Wraysbury</td>
<td>945</td>
<td>229</td>
<td>24.2%</td>
</tr>
<tr>
<td>Hurley and Walthams</td>
<td>1,004</td>
<td>281</td>
<td>28.0%</td>
</tr>
<tr>
<td>Maidenhead Riverside</td>
<td>1,254</td>
<td>359</td>
<td>28.6%</td>
</tr>
<tr>
<td>Old Windsor</td>
<td>1,011</td>
<td>333</td>
<td>32.9%</td>
</tr>
<tr>
<td>Oldfield</td>
<td>1,366</td>
<td>492</td>
<td>36.0%</td>
</tr>
<tr>
<td>Park</td>
<td>802</td>
<td>200</td>
<td>24.9%</td>
</tr>
<tr>
<td>Pinkneys Green</td>
<td>1,302</td>
<td>334</td>
<td>25.7%</td>
</tr>
<tr>
<td>Sunningdale</td>
<td>967</td>
<td>297</td>
<td>30.7%</td>
</tr>
<tr>
<td>Sunninghill and South Ascot</td>
<td>1,051</td>
<td>325</td>
<td>30.9%</td>
</tr>
<tr>
<td><strong>Windsor and Maidenhead</strong></td>
<td><strong>23,016</strong></td>
<td><strong>6,926</strong></td>
<td><strong>30.1%</strong></td>
</tr>
</tbody>
</table>

3 in 10 people aged 65 and over are living alone. This ranges from just over one fifth of the older people in Ascot and Cheapside to just over half of the older people in Castle Without.
69.7% of residents are living in homes that are owned outright or with a mortgage. 16.0% are privately renting and 1 in 8 residents (12.1%) are living in social rented accommodation including housing association properties. The remaining residents are either living rent free (1.7%) or in shared ownership accommodation (0.5%).

The highest concentrations of people living in social housing are in Oldfield (24.8%), Clewer South (21.0%) and Clewer North (20.5%). The lowest is in Maidenhead Riverside (5.4%).

22.5% of the population in RBWM are from Black and Minority Ethnic (BME) groups. By comparison, across the South East this figure is 14.8% and for England is 20.2%.

Boyn Hill has the largest proportion of BME residents in RBWM at 35.6%, followed by Maidenhead Riverside at 33.7%. Bisham and Cookham has the smallest proportion of BME residents at 9.6%.

The largest single BME category in RBWM is Other White at 7.0% of the population. The next largest is Indian (4.1%), followed by Pakistani (2.9%) and Other Asian (1.6%). Asian/Asian British categories make up 9.6% of the population, and are the largest non-White group. There are low numbers of people from Black backgrounds (1.2%).

The people in RBWM declare themselves to be predominantly Christian (62.3%). Those with no religion make up 21.7% of the population and 7.0% prefer not to say. The remaining 9.0% includes Muslim (3.9%), Sikh (2.0%), Hindu (1.8%), Buddhist (0.5%), Jewish (0.3%) and other religions (0.4%).

3.3 Health and health-related information

3.3.1 Deprivation
RBWM is ranked 303rd out of 326 local authorities in England for deprivation. Number 1 is the most deprived and 326 is the least deprived. Deprivation is ranked based on the Index of Multiple Deprivation (IMD) score. The score takes into account a range of different domains including income, employment, health, education, housing, access to services and crime.

Map 1 on Page 16 shows that none of RBWM’s 88 Lower Super Output Areas (LSOAs) are amongst the 20% most deprived in the country; however, levels of deprivation do vary with areas in Pinkneys Green, Belmont and Clewer North amongst the 40% most deprived in the country.

Map 2 shows this deprivation based on local quintiles, which more clearly shows the variation across the borough. The most deprived areas are scattered in the north and east of the borough.

---

10 BME includes White Irish, Gypsy and Irish Traveller, and Other White categories
11 LSOAs are a geography designed for reporting small area statistics
Maps showing deprivation in RBWM by Lower Super Output Area (LSOA) based on national and local quintiles; Source: IMD (2010)

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3.3.2 General health
As part of the 2011 Census, people were asked to assess whether their health was very good, good, fair, bad or very bad.

13.3% of people in RBWM said their health was ‘not good’ (fair, bad or very bad). Within wards, this ranges from 7.1% of people in Eton and Castle to 16.6% in Clewer North.

Figure 2 on the next page shows how people aged 65 and over responded – 41.9% of older people in RBWM said their health was ‘not good'; this ranges from 32.3% in Eton and Castle to 52.7% in Clewer East, and is better than the England average (50.6%) in all wards except Clewer East.

Life expectancy for both men and women in RBWM is higher than the England average. Life expectancy for males is 80.7 years (England – 78.9 years) and for females is 84.3 years (England – 82.9 years). Life expectancy is 6.1 years lower for men and 2.1 years lower for women in the most deprived areas than in the least deprived areas of the borough.

Over the last 10 years, all-cause mortality rates have fallen. Early death rates from heart disease and stroke have fallen and are better than the England average (53.1 per 100,000 pop, compared to England – 60.9 per 100,000 pop). Early death rates from cancer are better than the England average (94.5 per 100,000 pop compared to 108.1).\(^1\)

3.3.3 Limiting long-term illness
In the 2011 Census, people were asked if they had a long-term health problem or disability that limited their day-to-day activities, and has lasted, or is expected to last, at least 12 months. They were asked to assess whether their daily activities are limited a lot, a little or not at all.

42% of older people in RBWM said their health was ‘not good’. This ranges from 32% of older people in Eton and Castle to 53% in Clewer East.

45% of older people said their day-to-day activities are limited. This ranges from 37% of older people in Cox Green, to 57% in Clewer East.

12.7% of people in RBWM said their day-to-day activities are limited. This ranges from 7.4% in Eton and Castle, to 15.7% in Clewer North. Figure 3 on the next page shows that 44.7% of people aged 65 and over said their day-to-day activities are limited. This ranges from 36.7% of older people in Cox Green, to 57.1% of older people in Clewer East.

\(^1\) RBWM Health Profile (English Public Health Observatories, 2013)
Older people in RBWM aged 65 and over who say their health is ‘not good’; Source: Census (2011)

Older people in RBWM aged 65 and over who self-assess that they have a long term illness that limits their day-to-day activities; Source: Census (2011)
3.3.4 Hospital admissions
Heatherwood and Wrexham Park Hospitals NHS Foundation Trust provides hospital services to a wide population including Ascot, Bracknell, Maidenhead, Slough, South Buckinghamshire and Windsor. Figure 4 below shows the number of admissions over the last four years, alongside the number of emergency admissions.

The number of emergency admissions has been rising gradually; as a proportion of the number of admissions, emergency admissions have increased from 38.2% in 2009/10 to 41.7% in 2012/13.

Emergency admissions to hospital can sometimes be due to carer breakdown (see 4.4.5 Carer breakdown). If carers are better supported to remain in their caring role, this can prevent the need for the cared for to come to hospital or a non-emergency visit could be arranged. Obviously some admissions cannot be avoided.

Figure 4

![Admissions and emergency admissions](chart)

Admissions and emergency admissions, Heatherwood and Wrexham Park Hospitals NHS Foundation Trust; Source: Hospital Episode Statistics

3.3.5 End of life
At the end of life it is important that everyone receives high quality care and is supported to live and die well in their preferred place. The National End of Life Care Programme was established in 2004 to identify and disseminate best practice and a national strategy was developed in 2008. An important element of this was assessing and supporting the needs of carers both before and after the death of their loved one.
In April 2013, NHS Improving Quality (NHS IQ) was established to bring together the wealth of knowledge, expertise and experience of a number of NHS improvement organisations including the National End of Life Care Programme.

The National Bereavement Survey (VOICES) was commissioned by the Department of Health to monitor outcomes of the End of Life Care Strategy through a survey of bereaved relatives. The first survey was carried out in 2011 and a second survey was carried out in 2012. Results of the 2012 survey have only been published at a national level to date; however, analysis of the 2011 survey was by PCT cluster and provides overall scores for Berkshire.

Berkshire scored in the middle 60% of PCTs for support for carers while the patient was at home, sufficient help and support at time of death, and carers being involved in decisions as much as they wanted; however, it scores in the lowest 20% of PCTs for carers being able to discuss their worries or fears with their GP, and for carers talking to anyone from health, social care or a bereavement service since their loved one’s death.

There were 1,214 deaths registered in RBWM in 2012 – 583 males and 631 females. In 2011, this figure was 1,141 and 14.9% of deaths occurred when people were aged under 65; 42.6% occurred when people were aged 85 and over. Women live longer than men – only 31.4% of male deaths occurred aged 85 and over, against 52.4% of female deaths.

Half of the deaths in RBWM happen in hospital (49.9%) and 19.8% at home. 5.8% happen in a hospice and 22.9% in a care home. Compared to the England average, significantly less people die in hospital (England average is 54.5%) and significantly more die in a care home (17.8%).

3.4 Adults and children receiving statutory support

3.4.1 Adult Social Care

In 2012/13, 3,030 adults aged 18 and over received services provided or commissioned by RBWM. More than three quarters (78.2%) of adults received services provided to support clients living in the community, such as day care, home care, meals, or equipment. 12.2% were placed in long-term residential services and 9.6% were receiving nursing care. There may be some double counting amongst those if people moved into residential or nursing care during the year.

Figure 5 on the next page shows how this position has changed in the last five years. The number of people receiving community-based services has been falling since 2009/10 and is 39.4% lower in 2012/13 than in 2008/9. The number of people in long-term residential and nursing care placements has been steadier; however, the number of permanent admissions to residential and nursing care fell by more than a quarter in 2012/13 (11.8% for residential care and 36.0% for nursing care).\(^\text{13}\)

\(^\text{13}\) Adult Social Care Combined Activity Returns data (HSCIC, 2012/13)
In 2012/13, just under three quarters of community-based clients are aged 65 and over (72.7%) and just over a quarter (27.3%) are aged 18 to 64.

Just over three quarters of community-based clients (77.0%) have a physical disability as their primary need; this increases to 91.6% of clients aged 65 and over as physical conditions related to old age are more likely to become the primary need. 6.7% of older people have a mental health condition including dementia, 1.2% have a learning disability and 0.6% are classified as other.

For clients aged 18 to 64, 38.0% have a physical disability as their primary need, 34.9% have a learning disability and 27.1% have a mental health condition.

### 3.4.2 Children in need

The children in need census is an annual collection of data on children who have been referred to local authority social care services because their health or development is at risk of being significantly impaired without additional support.

There were 1,425 ‘children in need’ during 2012/13, with 715 on the books at the end of March 2013. This is equivalent to a rate of 216.2 per 10,000 children. Figure 6 on the next page shows how this figure and rate has changed in the last three years. Despite fluctuations in numbers, the rate has been fairly steady.

At the end of March 2013, 269 (37.6%) children in need had a disability recorded. Figure 7 on the next page shows the disability breakdown for those children who had a disability recorded. This shows that learning disabilities were most common (42.4%), followed by Autism/Asperger Syndrome (38.3%).
Figure 6

Number of children / rate per 10,000 pop

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of children in need at 31st March</th>
<th>Rate per 10,000 children at 31st March</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010/11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2011/12</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2012/13</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Children in need at 31st March between 2010 and 2013; Source: CIN Census*

Figure 7

Percentage of children reported with a disability

- Learning
- Autism/...
- Communication
- Mobility
- Behaviour
- Personal Care
- Incontinence
- Hand Function
- Other Disability
- Hearing
- Vision

*Children in need with a disability recorded at 31st March; Source: CIN Census*
3.4.3 Special Educational Needs

Some children have needs or disabilities that affect their ability to learn. These are called special educational needs (SEN). There are four different stages of support that children with SEN can go through:

- Early Years Action/School Action
- Early Years Action Plus/School Action Plus
- Assessment
- Statement of special educational needs

Some children with high needs can get an assessment right away and may get a statement. Statements say what the child’s needs are and are reviewed every year.\(^\text{14}\)

As at January 2013, 5,015 pupils in RBWM (19.1%) have SEN, including 712 (2.7%) with a statement. Figure 8 below shows a disability breakdown of those children with a statement or at School Action Plus, which shows that speech, language and communication are the highest needs (19.6%); followed by behaviour, emotional and social difficulties (17.0%); and moderate learning difficulties (16.7%).

Figure 8

<table>
<thead>
<tr>
<th>Disability</th>
<th>Percentage of children with SEN or at School Action Plus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech, Language and Communications Needs</td>
<td></td>
</tr>
<tr>
<td>Behaviour, Emotional &amp; Social Difficulties</td>
<td></td>
</tr>
<tr>
<td>Moderate Learning Difficulty</td>
<td></td>
</tr>
<tr>
<td>Autistic Spectrum Disorder</td>
<td></td>
</tr>
<tr>
<td>Specific Learning Difficulty</td>
<td></td>
</tr>
<tr>
<td>Other Difficulty/Disability</td>
<td></td>
</tr>
<tr>
<td>Physical Disability</td>
<td></td>
</tr>
<tr>
<td>Hearing Impairment</td>
<td></td>
</tr>
<tr>
<td>Profound &amp; Multiple Learning Difficulty</td>
<td></td>
</tr>
<tr>
<td>Visual Impairment</td>
<td></td>
</tr>
<tr>
<td>Severe Learning Difficulty</td>
<td></td>
</tr>
</tbody>
</table>

Children with special educational needs or at School Action Plus by disability; Source: SEN in England (2013)

\(^\text{14}\) The new Children and Families Act introduces changes to how children with SEN and their families are supported. These will come into force from September 2014.
3.5 Welfare benefits

3.5.1 Disability Living Allowance and Personal Independence Payment
Disability Living Allowance (DLA)\(^{15}\) is gradually being replaced by Personal Independence Payment (PIP)\(^{16}\) for people aged 16 to 64 – all new claims are for PIP instead of DLA.

DLA has been payable to people whose disability or health condition means they need help looking after themselves (the care component) and/or have walking difficulties (the mobility component). These difficulties must have lasted 3 months and be expected to last for at least 6 months.

To qualify for PIP you must be aged 16 to 64 and have a long-term health condition or disability and difficulties related to ‘daily living’ and/or mobility. The health condition or disability must have lasted 3 months and be expected to last for at least 9 months. Your claim is assessed by an independent health professional and if you are successful, your award is regularly reassessed.

If you look after someone who gets the middle or highest care component of DLA, or the PIP daily living component, then you may yourself be entitled to claim Carer’s Allowance (see 4.4.3 Financial impact).

There were 3,650 people claiming DLA in RBWM in August 2013, of which 1,455 were claiming the middle rate care component and 940 were claiming the higher rate care component. Figure 9 on the next page shows how the number of claimants of middle and higher rate care component has changed over the last decade. Both show an upward trend.

Figure 10 on the next page shows the number of claimants of middle and higher rate care component by ward as a snapshot in August 2013. This shows that Oldfield has the most claimants (185) and Eton and Castle has the least (20).

3.5.2 Attendance Allowance
Attendance Allowance is payable to people aged 65 and over who are severely physically or mentally disabled and need a great deal of help with personal care or supervision. It is paid at a lower or higher rate depending on the level of help that you need. If you are caring for someone who claims Attendance Allowance, you may yourself be entitled to claim Carer’s Allowance (see 4.4.3 Financial impact).

There were 2,580 people claiming Attendance Allowance in RBWM in August 2013. 12.5% of the population aged 65 and over are claiming it, rising to 37.1% of the population aged 85 and over, and 49.0% of the population aged 90 and over. Figure 11 on Page 26 shows how the number of claimants of higher and lower rate Attendance Allowance has changed over time. Over the last decade, there has been a general upward trend, which is more pronounced for higher rate claimants; in the last year, the number of higher rate claimants fell, and the number of lower rate claimants was steady.

\(^{15}\) https://www.gov.uk/dla-disability-living-allowance-benefit/overview
\(^{16}\) https://www.gov.uk/pip
Figure 9

Number of claimants of Disability Living Allowance in RBWM over the last ten years; Source: Nomis

Figure 10

Number of claimants of middle and higher rate Disability Living Allowance in RBWM by ward; Source: Nomis (August 2013)
**Figure 11**

*Number of claimants of Attendance Allowance in RBWM over the last ten years; Source: Nomis*
4. The availability, makeup and experiences of carers and the impacts of caring

This section sets out evidence to help us understand
- Who the local carers are, based on Census and national datasets
- The impacts local carers experience on their health and economic activity as a result of caring
- The makeup of young and young adult carers and the impacts on their caring role
- How many people are accessing carers’ benefits
- Experiences of carers as reported in national surveys

4.1 Introduction

In the UK, more than 6.5 million people care, unpaid, for friends or family members who are ill, frail or disabled. These carers are an essential component of the health and social care economy and save the state an estimated £119 billion per year – more than the annual cost of the NHS. In RBWM alone, the contribution of almost 13,000 carers was estimated to be worth more than £191.5 million per year.\textsuperscript{17} The care they provide to help sustain people in their own homes and in their own communities is absolutely vital. Without it, our health and social care systems simply could not cope with demand.

However, as a result of caring, carers can suffer negative impacts to their health and wellbeing; and their participation in work, education and training can be compromised. Without effective support, the caring role itself can become unsustainable.

This chapter provides demographic information about carers in RBWM, and the impacts they face as a result of caring.

4.2 Availability of carers

The 2011 Census asked if a person looked after or gave any unpaid help or support to family members, friends, neighbours or others because of long term physical or mental ill-health/disability or problems related to old age.

There were 13,235 carers in RBWM at the time of the 2011 Census. This number has increased by 15.1% since 2001 – which is much faster than the rise in overall population (8.2%). Carers make up 9.2% of the total population in RBWM, compared to 9.8% of the population in the South East and 10.2% across England.

\textsuperscript{17} Valuing Carers (Carers UK and University of Leeds, 2011) – calculation is based on a methodology that uses an official estimate of actual cost per hour of providing home care to an adult
Table 2 below shows the number of carers in each ward in RBWM and the percentage of the population who provide unpaid care. The 6 areas with the most carers and the highest percentage of carers in the population have been highlighted.

Within wards, the percentage of carers in the population varies from 5.5% in Eton and Castle to 10.8% in Bisham and Cookham. In terms of actual numbers, the smallest carer population is in Eton and Castle (152 people) and the largest is in Clewer North (776 people).

There does not appear to be an overall correlation between concentrations of carers and any particular type of housing tenure.

Table 2

<table>
<thead>
<tr>
<th>Area</th>
<th>Population</th>
<th>Provides care</th>
<th>% providing care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ascot and Cheapside</td>
<td>5,702</td>
<td>484</td>
<td>8.5%</td>
</tr>
<tr>
<td>Belmont</td>
<td>8,315</td>
<td>722</td>
<td>8.7%</td>
</tr>
<tr>
<td>Bisham and Cookham</td>
<td>6,878</td>
<td>741</td>
<td>10.8%</td>
</tr>
<tr>
<td>Boyn Hill</td>
<td>7,798</td>
<td>699</td>
<td>9.0%</td>
</tr>
<tr>
<td>Bray</td>
<td>7,483</td>
<td>712</td>
<td>9.5%</td>
</tr>
<tr>
<td>Castle Without</td>
<td>6,952</td>
<td>472</td>
<td>6.8%</td>
</tr>
<tr>
<td>Clewer East</td>
<td>5,450</td>
<td>455</td>
<td>8.3%</td>
</tr>
<tr>
<td>Clewer North</td>
<td>7,728</td>
<td>776</td>
<td>10.0%</td>
</tr>
<tr>
<td>Clewer South</td>
<td>5,341</td>
<td>463</td>
<td>8.7%</td>
</tr>
<tr>
<td>Cox Green</td>
<td>7,505</td>
<td>706</td>
<td>9.4%</td>
</tr>
<tr>
<td>Datchet</td>
<td>4,913</td>
<td>475</td>
<td>9.7%</td>
</tr>
<tr>
<td>Eton Wick</td>
<td>2,260</td>
<td>206</td>
<td>9.1%</td>
</tr>
<tr>
<td>Eton and Castle</td>
<td>2,748</td>
<td>152</td>
<td>5.5%</td>
</tr>
<tr>
<td>Furze Platt</td>
<td>7,393</td>
<td>713</td>
<td>9.6%</td>
</tr>
<tr>
<td>Horton and Wraysbury</td>
<td>5,063</td>
<td>522</td>
<td>10.3%</td>
</tr>
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<td>Hurley and Walthams</td>
<td>6,129</td>
<td>630</td>
<td>10.3%</td>
</tr>
<tr>
<td>Maidenhead Riverside</td>
<td>7,713</td>
<td>747</td>
<td>9.7%</td>
</tr>
<tr>
<td>Old Windsor</td>
<td>4,977</td>
<td>527</td>
<td>10.6%</td>
</tr>
<tr>
<td>Oldfield</td>
<td>9,141</td>
<td>754</td>
<td>8.2%</td>
</tr>
<tr>
<td>Park</td>
<td>5,290</td>
<td>448</td>
<td>8.5%</td>
</tr>
<tr>
<td>Pinkneys Green</td>
<td>7,392</td>
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<td>5,347</td>
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<td>589</td>
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<tr>
<td><strong>Windsor and Maidenhead</strong></td>
<td><strong>144,560</strong></td>
<td><strong>13,235</strong></td>
<td><strong>9.2%</strong></td>
</tr>
</tbody>
</table>

Provision of unpaid care in RBWM; Source: Census (2011)
Map 3 below shows the numbers of people who provide unpaid care by Lower Super Output Area (LSOA). This shows higher concentrations of carers in areas of Bisham and Cookham, Hurley and Walthams, Boyn Hill, Clewer South, Old Windsor, Horton and Wraysbury, Ascot and Cheapside, and Sunningdale. The lowest concentrations of carers are in areas around Windsor Castle.

Map 3

Map of RBWM showing the number of people who provide unpaid care by Lower Super Output Area; Source: Census (2011)
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The Survey of Carers in Households in England 2009/10\(^{18}\) identified that carers are now caring for more hours than they were in 2001 and that this adversely affects their health and quality of life. The results from the 2011 Census corroborate this and show that nationally, and in RBWM, carers are caring for longer. There has been a 29.3% increase nationally and a 39.0% increase in RBWM in the numbers of people caring for 20 or more hours per week; this compares to a 3.1% national increase and an 8.0% local increase in numbers of people caring for less than 20 hours.

Table 3 on the next page shows the number of carers in RBWM by the hours of care they provide each week. 27.4% of carers in RBWM provide care for more than 20 hours per weeks; the 6 areas with the largest population of this group have been highlighted. This is lower than across the South East (31.9%) and England (36.4%). 16.6% of carers provide care for more than 50 hours per week. This is also lower than the South East (20.5%) and England (23.1%).

Nationally, and in RBWM, carers are caring for longer. There has been a 39% increase in the numbers of people caring for 20 or more hours per week in RBWM, compared to an 8% increase in those caring for less than 20 hours.

Figure 12 below shows the balance of hours of care provided per week by carers in each of the wards in RBWM. Clewer East has the highest proportion of carers in a high intensity caring role compared to other wards, with 33.8% providing more than 20 hours of care per week and 21.3% providing more than 50 hours. Carers in high intensity roles are likely to have more support needs (see 4.4 Impacts of caring).

---

\(^{18}\) http://www.hscic.gov.uk/pubs/carersurvey0910
<table>
<thead>
<tr>
<th>Area</th>
<th>1-19 hours</th>
<th>20-49 hours</th>
<th>50+ hours</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ascot and Cheapside</td>
<td>363</td>
<td>38</td>
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<td>484</td>
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<tr>
<td>Belmont</td>
<td>495</td>
<td>95</td>
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<td>722</td>
</tr>
<tr>
<td>Bisham and Cookham</td>
<td>553</td>
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<td>119</td>
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<td>Boyn Hill</td>
<td>501</td>
<td>83</td>
<td>115</td>
<td>699</td>
</tr>
<tr>
<td>Bray</td>
<td>538</td>
<td>69</td>
<td>105</td>
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<td>Castle Without</td>
<td>355</td>
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<td>56</td>
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<td>97</td>
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<td>85</td>
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<td>Cox Green</td>
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<td>70</td>
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<td>Eton and Castle</td>
<td>121</td>
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<td>50</td>
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<td>128</td>
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<tr>
<td>Sunningdale</td>
<td>403</td>
<td>51</td>
<td>68</td>
<td>522</td>
</tr>
<tr>
<td>Sunninghill and South Ascot</td>
<td>446</td>
<td>65</td>
<td>78</td>
<td>589</td>
</tr>
<tr>
<td><strong>Windsor and Maidenhead</strong></td>
<td><strong>9,604</strong></td>
<td><strong>1,432</strong></td>
<td><strong>2,199</strong></td>
<td><strong>13,235</strong></td>
</tr>
</tbody>
</table>

*Carers in RBWM by hours of care provided per week; Source: Census (2011)*
4.3 Makeup of carers

Anyone can become a carer and this section shows that carers in RBWM come from all backgrounds and can be of any age. Carers support a multitude of conditions. Some of the impacts of caring (see 4.4 Impacts of caring) are common to all carers; however, some carers experience different impacts and issues to others.

4.3.1 Specific groups of carers
Some common groups of carers include:

- **Carers of adults with specific conditions**
  Some of the impacts and issues associated with caring for an adult can be quite different depending on the conditions of the person that the carer is supporting, and carers may be dealing with a number of different conditions at the same time. Some of the most prevalent groups of carers include:

  - Carers of adults with a mental health problem
  - Carers of adults with substance misuse issues or ‘dual diagnosis’
  - Carers of adults with learning disabilities
  - Carers of adults with long-term conditions
  - Dementia carers
  - End of life carers (see also 3.3.5 End of life)

- **Working and working age carers**
  1 in 9 people in the paid workforce are caring for someone who is ill, frail or has a disability. Carers who are in employment may need extra support to juggle work and care. Working age carers are far more likely to be ‘sandwich’ carers who combine looking after young children with caring for older or disabled family members.

- **Older carers**
  Carers aged 65 and over who look after a partner, adult child, other relative or friend in later life. Also includes the ‘oldest old’ – a rapidly growing generation aged 85 and over. Older carers may be co-caring e.g. two people caring for each other.

- **Carers from different equality groups**
  Some carers from different equality groups (e.g. BME, LGBT) will face common issues different to other groups, including stigma and lack of understanding (see 4.3.3 Ethnicity of carers, 4.3.4 LGBT carers and 4.3.5 Religion and carers).

- **Young carers** (see 4.5 Young and young adult carers)

- **Parent carers** (see 4.6 Parent carers)
4.3.2 Age and gender of carers

Figure 13 below shows the distribution of carers and non-carers in RBWM by gender. 42.6% of carers are male and 57.4% are female. 6 in 10 people (61.0%) providing unpaid care for more than 50 hours per week are female.

The peak age for caring is between 50 and 64; 19.4% of that age group are providing care and 38.5% of carers are in that age group.

Figure 14 on the next page shows the proportion of the carer population in each ward by broad age groups:

- Young carers aged 0-15
- Working age carers aged 16-64
- Older carers aged 65 and over

This shows that there are higher concentrations of young carers in Eton and Castle, Park and Datchet; higher concentrations of working age carers in Castle Without, Eton and Castle and Clewer East; and higher concentrations of older carers in Clewer North, Bisham and Cookham and Old Windsor.

Figure 13

Distribution of RBWM population and carer population by gender; Source: Census (2011)
Figure 14

Makeup of the carer population in RBWM by age and ward; Source: Census (2011)
Figure 15 below shows the varied age profile of a carer in RBWM as the intensity of their role changes. The age profile of the general population and that of non-carers is included for comparison purposes. As the caring role gets more intensive, the proportion of older carers increases. Of those people who provide 20 or more hours of unpaid care per week, 34.4% are aged 65 and over; of those who provide 50 or more hours per week, 42.3% are aged 65 and over.

In real terms, the 2011 Census identified 1,251 people aged 65 and over providing 20 or more hours of unpaid care per week in RBWM, including 931 who are providing 50 or more hours. This is likely to be a group with high needs.

**Figure 15**

<table>
<thead>
<tr>
<th>Hours of Care</th>
<th>Carers</th>
<th>Non-carers</th>
<th>All people</th>
</tr>
</thead>
<tbody>
<tr>
<td>50+</td>
<td>29.9%</td>
<td>16.2%</td>
<td>23.5%</td>
</tr>
<tr>
<td>20-49</td>
<td>27.9%</td>
<td>31.5%</td>
<td>26.5%</td>
</tr>
<tr>
<td>1-19</td>
<td>25.5%</td>
<td>26.7%</td>
<td>24.8%</td>
</tr>
<tr>
<td>Carers</td>
<td>20.7%</td>
<td>25.6%</td>
<td>24.8%</td>
</tr>
<tr>
<td>Non-carers</td>
<td>39.3%</td>
<td>27.5%</td>
<td>32.7%</td>
</tr>
<tr>
<td>All people</td>
<td>23.4%</td>
<td>27.3%</td>
<td>25.7%</td>
</tr>
</tbody>
</table>

*Distribution of RBWM population and carer population by age; Source: Census (2011)*

**4.3.3 Ethnicity of carers**

Research has shown that nationally, BME carers provide proportionately more high intensity unpaid care than White British carers, putting them at greater risk of ill-health, isolation, loss of paid employment and social exclusion.

There are also likely to be higher numbers of hidden carers in BME communities – this may be due to language and literacy barriers, stigma attached to certain conditions, cultural barriers that hinder access to services (e.g. notions of duty to care), or misconceptions about extended family support.21

In RBWM, 16.7% of the carer population are from BME groups. Figure 16 on the next page shows that this ranges from 7.0% of the carer population in Bisham and Cookham to 29.9% of the carer population in Boyn Hill.

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21 Half a Million Voices: Improving Support for BAME Carers (Carers UK, 2011)
6.8% of the BME population provide unpaid care, compared to 9.8% of the White British population. This ranges from 2.8% of the Mixed White and Black African population, to 9.8% of the White Irish population. Figure 17 below shows the actual number of carers in each ethnic group. This shows the largest BME carer populations are in the Other White, Pakistani and Indian groups.

**Figure 16**

![Bar chart showing percentage of RBWM carer population who are from BME groups; Source: Census (2011)](chart16)

**Figure 17**

![Bar chart showing number of BME people who provide unpaid care, by ethnic group; Source: Census (2011)](chart17)
4.3.4 LGBT carers
For lesbian, gay, bisexual or transgender (LGBT) carers, feelings of isolation or worry about services not being LGBT friendly, may lead to many staying hidden and not accessing support. There can also be issues with partners not being recognised or discrimination from other family members, or cultural and religious groups.

LGBT carers and people who require care may feel out of place in traditional support groups or be anxious about accessing services due to fears of homophobia or not having their specific needs met. Older gay people are more likely to be single and to live on their own and have less of a family support group.22 23

LGBT carers are likely to be a hidden group in RBWM, as are LGBT people needing care. Unfortunately, there is little solid evidence on the demographics of sexual orientation in local communities, and there are few studies on the numbers of LGBT carers.

Often it is difficult to accurately measure something such as sexual identity or gender identity as it depends on how comfortable the person feels with revealing the information at the time. However, this should not prevent monitoring taking place – there may just be a need for more care and sensitivity around it. Having processes in place to proactively support LGBT carers and service users can make all the difference.

4.3.5 Religion and carers
Religion can also have a bearing on whether people feel comfortable accessing services or not. Research has shown that carers in certain religious communities will sometimes pay for private services because they need to ensure the religious requirements of the service user are met. There can also be a stigma attached to mental health and other conditions in some communities.24

With 71.3% of the population in RBWM having a religion – and 9.0% having a religion other than Christian – there are likely to be some hidden carers amongst these groups.

4.4 Impacts of caring

4.4.1 Health and wellbeing
Caring for others can adversely affect your health and wellbeing and research has shown that carers are significantly more likely to be in poor physical and emotional health than those without caring responsibilities.

22 http://www.nhs.uk/CarersDirect/carerslives/aboutcaring/Pages/out-and-caring.aspx
23 https://www.stonewall.org.uk/what_we_do/research_and_policy/health_and_healthcare/3480.asp
24 Half a Million Voices: Improving Support for BAME Carers (Carers UK, 2011)
Research by Carers UK in 2013 showed that 84% of carers had seen their health negatively impacted by their caring responsibilities. This was up from 74% in 2012. 92% of carers said that their mental health had been affected by caring.  

The 2013 Carers Week report ‘Prepared to Care?’ also highlighted the negative impact of caring on carers’ health and wellbeing. 61% of carers have suffered from depression and 92% feel more stressed because of their caring role.  

1 in 5 carers (20.2%) in RBWM report being in ‘not good’ health, compared to 1 in 8 non-carers (12.1%). Almost a third (31.6%) of people providing 20 or more hours of unpaid care per week report being in ‘not good’ health; this increases to just over a half (51.2%) of carers aged 65 and over (against 40.3% for non-carers aged 65 and over).  

Figure 18 below shows how the health of carers and non-carers compares, demonstrating the poorer health outcomes for carers as their caring role intensifies.  

Figure 18  

<table>
<thead>
<tr>
<th>Percentage of people with ‘not good’ general health</th>
<th>Non-carer</th>
<th>1 to 19 hours</th>
<th>20 or more hours</th>
<th>50 or more hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of people with ‘not good’ general health</td>
<td>All ages</td>
<td>65 and over</td>
<td>All ages</td>
<td>65 and over</td>
</tr>
<tr>
<td>Non-carer</td>
<td>10.0%</td>
<td>10.0%</td>
<td>10.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td>1 to 19 hours</td>
<td>10.0%</td>
<td>10.0%</td>
<td>10.0%</td>
<td>10.0%</td>
</tr>
<tr>
<td>20 or more hours</td>
<td>20.0%</td>
<td>20.0%</td>
<td>20.0%</td>
<td>20.0%</td>
</tr>
<tr>
<td>50 or more hours</td>
<td>30.0%</td>
<td>30.0%</td>
<td>30.0%</td>
<td>30.0%</td>
</tr>
</tbody>
</table>

Figure 18 shows the percentage of carers and non-carers who report their health as ‘not good’. Source: Census (2011)  

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25 The State of Caring (Carers UK, 2013)  
26 Prepared to Care? (Carers Week, 2013)  
27 Responses of ‘fair’, ‘bad’ and ‘very bad’ represent ‘not good’ health
In real numbers, 2,662 carers (including 1,207 aged 65 and over) declare their health to be 'not good'. This includes 539 carers (255 aged 65 and over) who declare their health to be bad or very bad. Figure 19 below shows the numbers of carers and older carers in 'not good' health in each ward.

**Figure 19**

![Chart showing numbers of carers and older carers in 'not good' health by ward.](chart.png)

*Number of carers who say their health is 'not good' by ward; Source: Census (2011)*

See also **4.7.2 GP Patient Survey.**

**4.4.2 Participation in work, education and training**

More than half (2.8 million) of England’s 5.3 million carers aged 16 and over, juggle work and care. Research shows that 45% of carers have given up work because of their caring role and 42% have reduced their working hours.\(^{28}\)

Nearly two thirds (65%) of carers in work have used annual leave to care while, nearly half (47%) have worked overtime to make up for taking time off to care. One in seven carers (15%) have taken a less qualified job or turned down promotion because of caring responsibilities. A further one in six carers (17%) continues to work the same hours but find their job is negatively affected by stress, tiredness or lateness. Over half (56%) of carers who gave up work to care spent or have spent over five years out of work as a result.\(^{29}\)

In RBWM, the proportion of carers aged 16 and over in full-time employment is 38.2%, lower than the 48.9% of non-carers aged 16 and over. Carers are more likely

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\(^{28}\) Prepared to Care? (Carers Week, 2013)

\(^{29}\) The State of Caring (Carers UK, 2013)
to be in part-time employment; 19.5% of carers are in part-time work against 14.3% of non-carers.

As you would expect, Figure 20 below shows that the proportion of carers in employment differs significantly depending on the intensity of their caring role. Almost a third (32.5%) of people providing unpaid care for 50 or more hours a week are in employment, against almost two thirds (63.9%) of people providing unpaid care for 1-19 hours a week.

17.8% of people who provide care for 50 or more hours per week are also in full time employment (388 people) and are likely to be a group with high support needs.

Figure 20

People in paid employment in RBWM by hours of care provided per week; Source: Census (2011)
4.4.3 Financial impact

National research has shown that carers are facing serious and lasting financial consequences due to the extra costs of caring. Almost half are cutting back on essentials like food (45%) and heating (44%). A fifth are unable to afford their rent or mortgage payments (19%) and are using their overdraft (22%) or credit cards (20%) to make ends meet. More than half (53%) say their money worries are taking a toll on their health.\(^{30}\)

Carers eligible for Carer’s Allowance\(^ {31}\) – a financial benefit worth £59.75 – must care for 35 hours or more a week and earn less than £100 a week after tax. Other criteria include the carer being aged over 16 and not in full-time education, and the person being looked after receiving a qualifying disability benefit (see 3.5 Welfare benefits).

Figure 21 below shows that there were 720 carers claiming Carer’s Allowance in RBWM in August 2013, equivalent to £2,237,040 annually. The number of claimants has increased in the last ten years, correlating with an increase in high intensity caring.

In 2013, Carers UK analysed the number of carers who are likely to be missing out on Carer’s Allowance using existing claimant count figures and take-up rate. Across the UK, they estimated 360,000 carers are missing out on £1.1 billion in Carer’s Allowance every year. In RBWM, an estimated 377 carers are missing out on a total of £1,171,100 every year.\(^ {32}\)

Figure 21

\(^{30}\) Caring & Family Finances Inquiry (Carers UK, 2014)
\(^{31}\) https://www.gov.uk/carers-allowance/
\(^{32}\) http://www.carersuk.org/professionals/resources/research-library/item/3353-carersallowancetakeup
4.4.4 Social isolation

Carers can often experience loneliness and isolation as a result of their caring role, and when their caring role comes to an end. The 2013 Carers Week report ‘Prepared to Care?’ talked about the risk of isolation that carers face – particularly those who are providing significant hours of care a day – and how this can result in the degradation of their own health. It reinforced the need for and benefits of more social support being offered to carers.33

In a recent survey, more than two thirds of adult carers in RBWM said they have some social contact but not enough or little social contact and feel social isolated (see 4.7.1 National Carers’ Survey).

Research in 2011 funded by the Department of Health34 recognised social isolation as a significant problem for carers of people with dementia. The report identified activities that can have a positive impact on carers’ social isolation, including:

- Volunteer befrienders
- Peer support and groups
- Counselling, including relationship counselling
- Education and courses about leisure activities, stress management, dementia, communicating with someone with dementia and managing challenging behaviour
- The opportunity to tell their own story and reminisce

Social isolation can be a particular problem in some BME groups due to stigma, language and literacy barriers. National research showed that Pakistani and Bangladeshi carers experience greater levels of isolation.35 The 2011 Census revealed that there are more than 300 carers of Pakistani origin living in RBWM.

Social isolation can be particularly prevalent for young carers (see 4.5 Young and young adult carers), who often miss out on opportunities to socialise with friends due to the pressures of their caring role, or even face bullying for being ‘different’. Family Action36 – who runs a service for young carers in RBWM (see 5.5 Young carers known to Family Action) – says that this can lead to feelings of loneliness, anxiety and frustration. Young people may be afraid to ask for help, for fear of upsetting their family, or being taken into care. They are often unable to attend after-school activities, or go on school trips, and they may find it difficult to concentrate at school or decide not to go to school at all.

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33 Prepared to Care? (Carers Week, 2013)
34 The Needs of Informal Carers of Those Living with Dementia (Hull Churches Home from Hospital Services, 2011)
35 Half a Million Voices: Improving Support for BAME Carers (Carers UK, 2011)
36 http://www.family-action.org.uk
4.4.5 Carer breakdown

The previous sections have demonstrated the potential negative impacts of caring on carers’ health, wellbeing, social life, finances and participation in work. Sometimes the negative impacts of caring can lead to the caring role breaking down completely; this can be a sudden deterioration or a gradual process over time.

Carer breakdown leads to costly interventions for health and social care, who must step in to take over the care and support provided by the carer, and potentially support them as a service user too. It should be considered a significant risk to local authorities and the NHS at a time when resources are already stretched, and a priority to mitigate it with appropriate support.

If social care has to step in to provide replacement care, the costs can soon escalate. For example, the average weekly cost per person for home care in RBWM is £282. For older people, it's £183. For an adult with a learning disability it is £750.\(^{37}\)

In some cases, carer breakdown may lead to the cared for needing to go into residential or nursing care. A national study in 2001\(^ {38}\) of almost 2,500 people admitted to residential and nursing care showed that carer-related reasons for admission were common. Reasons including stress on carers and family breakdown were given in 40% of cases overall.

Nursing care in RBWM costs on average £549 per older person per week; residential care costs £495. For adults with a learning disability in residential and nursing care, it costs £1,332 per person per week.\(^ {39}\)

Carer breakdown can also cause additional expense through emergency hospital admissions (see 3.3.4 Hospital admissions). One example could be where someone has an accident or a fall at home as a result of no carer being present to prevent it happening or reduce the impact. Health and social care will have to shoulder the cost of emergency care, any ongoing treatment, and potentially a short or long term stay in residential care.

Carers should be appropriately supported and informed while their cared for is in hospital and as part of the discharge process; this can help to prevent a costly readmission.

Research by Marie Curie Cancer Care\(^ {40}\) recommended that local authorities do more to promote the support and emergency services they offer which prevent carer breakdown when someone is looking after someone at the end of life. The study warned that carer breakdown can lead to an emergency admission to hospital, for both the carer and the cared for, and potentially to the cared for not achieving their preferred place of death.

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\(^{37}\) Personal Social Services: Expenditure and Unit Costs, England – Final release (HSCIC, 2012-13)

\(^{38}\) Care Homes for Older People: Volume 2 Admissions, Needs and Outcomes (PSSRU, 2001)

\(^{39}\) Personal Social Services: Expenditure and Unit Costs, England – Final release (HSCIC, 2012-13)

\(^{40}\) Committed to Carers: Supporting carers of people at the end of life (Marie Curie Cancer Care, 2012)
4.5 Young and young adult carers

Young carers are children and young people who help to look after family members who have a disability, illness, mental health condition, or substance misuse problem. They often take on responsibilities that would not normally be expected of someone their age.

3 in 10 people in RBWM (around 42,270 people) are aged under 25, including 2 in 10 that are aged under 16 (around 29,150 people). This ranges from almost a quarter of the people (23.7%) in Castle Without to almost a half of the people (48.7%) in Eton and Castle being aged under 25.

There were 750 young and young adult carers aged under 25 in RBWM identified by the 2011 Census (1.8% of the under 25 population), including 225 young carers aged under 16. Figure 22 below shows that the largest identified population is in Oldfield (58 carers) and the smallest is in Eton Wick (9 carers).

Table 4 on the next page shows the distribution of these young and young adult carers by age and intensity of caring role. This shows that the majority of young carers (79.5%) provide unpaid care for 1 to 19 hours per week. 154 young carers aged under 25 are identified as providing more than 20 hours of care per week and are likely to be a group with high support needs.

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41 Mid-2012 Population Estimates (ONS, 2013)
Table 4

<table>
<thead>
<tr>
<th>Group</th>
<th>Aged 0 to 15</th>
<th>Aged 16 to 24</th>
<th>Under 25</th>
</tr>
</thead>
<tbody>
<tr>
<td>All young people</td>
<td>28,660</td>
<td>13,606</td>
<td>42,266</td>
</tr>
<tr>
<td>Young carers</td>
<td>225 (0.8%)</td>
<td>525 (3.9%)</td>
<td>750 (1.8%)</td>
</tr>
<tr>
<td>1 to 19 hours per week</td>
<td>186</td>
<td>410</td>
<td>596</td>
</tr>
<tr>
<td>20 to 49 hours per week</td>
<td>22</td>
<td>70</td>
<td>92</td>
</tr>
<tr>
<td>50 or more hours per week</td>
<td>17</td>
<td>45</td>
<td>62</td>
</tr>
</tbody>
</table>

*Distribution of young carers by age and intensity of caring role; Source: Census (2011)*

Caution should be exercised when looking at these figures as they are likely to be an underestimate, dependent on the person who completed the Census questionnaire recognising or being willing to declare the caring role of the child or young person.

In 2010, new research published by the BBC\(^42\) following a survey of over 4,000 secondary school pupils showed that there was a “hidden army” of young people taking on caring roles. Around 1 in 12 of those surveyed had moderate to high levels of caring responsibilities – applying this ‘rule of thumb’ to the population in RBWM means there could be as many as 2,700 young carers aged under 18.

ONS research in 2013 highlighted growing evidence pointing to the adverse effects of providing care on the health, future employment opportunities and social and leisure activities of young people. Young carers in the South East providing 50 or more hours of care per week were found to be 5.9 times more likely than those providing no care to report their general health as ‘not good’.\(^43\)

In RBWM, young carers experience poorer health outcomes than their non-carer peers, with young carers aged under 25 being 2.6 times more likely to report their health as ‘not good’.

### 4.6 Parent carers

Parents or carers of a child with a disability or additional needs are often called parent carers. Parent carers have generally been recognised to be supporting children and young people aged under 18.

For a long time, there has been a rights gap between parent carers and other carers; however, the Children and Families Act includes new rights which will make it easier for parent carers to be assessed and supported. It also introduces a new ‘birth-to-25 years’ Education, Health and Care Plan (EHC) for children and young people with special educational needs.

In RBWM from the age of 14, young people begin to plan for the transition into adulthood and into adult services, if they are likely to have future support needs. This


\(^43\) Providing unpaid care may have an adverse effect on young carers’ general health (ONS, 2013)
involves children and adult services working closely together and clearly identifying the young person’s outcomes such as education and employment opportunities.

Transition can be a stressful and uncertain time for all involved. Transitions need to be carefully managed and planned so that those involved feel supported and do not drop out of services or feel they are no longer able to cope. An average of 17 young people transfer to adult services in RBWM every year; these are mostly young people with learning disabilities.44

Census data does not specifically identify parent carers of disabled children; however, there are 663 children aged 0-15 and 491 young people aged 16-24 living in households in RBWM with an illness or disability that limits their day-to-day activity. Figure 23 below and Figure 24 on the next page show the number of children and young people in each ward with a limiting long-term illness. This implies there may be higher numbers of parent carers of children in areas such as Furze Platt, Belmont, and Bisham and Cookham.

"Being the parent of a disabled child brings with it unique challenges, and we must not underestimate the contribution that parent carers of disabled children make. I am delighted that...we have been able to clarify and strengthen the rights of these families in law and make it clear that councils must take into account the full and complex needs of parent carers."
Edward Timpson, Minister for Children and Families (2014)

Figure 23

Number of children aged 0-15 with a limiting long-term illness by ward; Source: Census (2011)

44 http://www.rbwm.gov.uk/web/jsna_transition.htm
4.7 Carers’ experience surveys

4.7.1 National Carers’ Survey
In 2012/13, RBWM participated in the mandatory Personal Social Services User Experience Survey of Carers. The survey captures carers’ thoughts and opinions on a variety of topics that are considered to be indicative of a balanced life alongside their caring role. The survey will be repeated biennially and the results will be used to inform national policy.

Councils sent questionnaires to a random sample of carers of service users in receipt of services funded either in whole or in part by their council. The carers had to have had an assessment or reassessment of their needs in the 12 months before the sample was drawn.

In RBWM, 209 questionnaires were completed out of an eligible population of 430. Two thirds of respondents (66.7%) were caring for someone aged 65 and over and the conditions being supported included physical disabilities (53.1%), dementia (40.6%), mental health problems (25.6%) and substance misuse (2.4%).

Most carers had been in their caring role for more than one year (97.0%), with 61.2% more than five years, 42.6% more than ten years, and 23.0% more than twenty years. A majority of carers provided more than 20 hours of care per week (73.4%) and almost half provided more than 50 hours per week (48.9%).
One fifth of the carers (20.5%) said they had a physical impairment or disability, or a long-standing illness (19.4%). 12.8% said they suffered from sight or hearing loss and 6.7% said they had a mental health problem.

6 in 10 carers (59.8%) were retired, and just under a quarter (24.1%) were in paid employment (12.8% full-time). A quarter of those carers in paid employment (25.2%) said they did not feel supported in their caring role by their employer.

Data from the survey feeds into the Adult Social Care Outcomes Framework and populates the following outcome measures:

- 1D: Carer reported quality of life
- 3B: Overall satisfaction of carers with social services
- 3C: The proportion of carers who report they have been included or consulted in discussions about the person they care for
- 3D: The proportion of people who use services and carers who find it easy to find information about services

Carer reported quality of life (1D) is a composite measure combining responses to six questions in the survey covering the domains of occupation, control, personal care, safety, social participation, and encouragement and support. There is an equivalent measure for service users (1A – Social care-related quality of life).

Respondents are given a score based on their answers to the six questions. Each question has three answers (‘no needs met’ = 0, ‘some needs met’ = 1 and ‘no unmet needs’ = 2). These scores are then summed and divided by the total number of respondents who answered all six questions. Therefore, a higher score means a better quality of life.

RBWM scored 8.0 for carer reported quality of life. Nationally, the results ranged from 6.6 to 9.8, with both the England and South East average being 8.1. Figure 25 on the next page shows how RBWM’s result compared to its comparator45 local authorities. It scored below the group average (8.2).

Looking at the quality of life domains individually for those carers with no unmet needs, RBWM scored below average against its comparator group in five out of the six domains. Personal Care was its highest result against comparators, with 63.2% of carers saying they have no personal care needs and are able to look after themselves.

RBWM scores below average for all domains except Personal Care with regard to those carers with unmet needs (including low and high needs). It scores low for Occupation, with 85.0% of carers saying they either don’t do enough or don’t do anything they value or enjoy with their time.

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45 Comparator group uses CIPFA’s Nearest Neighbours Model, which adopts a scientific approach to measuring the similarity between local authorities.
anything they value or enjoy with their time. Similarly, for the Social domain, 68.5% of carers say they have some social contact but not enough or little social contact and feel social isolated (see also 4.4.4 Social isolation). For both of these domains, only Wiltshire has a worse result.

Figures 26, 27 and 28 on the following pages show RBWM’s result against comparators for the other outcome measures from the Adult Social Care Outcomes Framework. RBWM’s performance is below comparator group average for each of these.

Figure 25

Carer-reported quality of life

Carer reported quality of life; Source: PSS User Experience Survey of Carers (2012/13)
Figure 26

Overall satisfaction of carers with social services

Satisfaction of carers with social services; Source: PSS User Experience Survey of Carers (2012/13)

Figure 27

Proportion of carers who report that they have been included or consulted in discussion about the person they care for

The proportion of carers who report they have been included or consulted in discussions about the person they care for; Source: PSS User Experience Survey of Carers (2012/13)
4.7.2 **GP Patient Survey**

The GP Patient Survey gives patients the opportunity to comment on their experiences of their local GP surgery, local health services and their general health. The survey is sent out twice a year – in January and July – to a random selection of adult patients registered with a GP in England.

Data from the 2013 publication was collected during January-March and July-September 2013. The questionnaire asks respondents if they 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. It is therefore possible to break down the answers for all questions for carers and non-carers.

Respondents were asked to rate their last GP appointment in terms of the GP:

- Giving you enough time
- Listening to you
- Explaining tests and treatments
- Involving you in decisions about your care
- Treating you with care and concern

For WAM CCG, responses from carers and non-carers were positive for all of the above. As an average across all five areas, 82.3% of non-carers rated their experiences as good/very good, compared to 80.6% of carers. These positive results are reflected similarly in national results.
In terms of having confidence and trust in their GP, non-carers and carers were both very positive with 93.9% of non-carers and 94.5% of carers responding ‘yes, definitely’ or ‘yes, to some extent’. Again, this is similarly high across the country.

Their overall experience of the GP surgery begins to show some difference of opinion, with 84.4% of non-carers rating this as very/fairly good, against 76.7% of carers. Although both results are high, this does differ from national results with non-carers at 86.0% and carers at 85.6%.

The difference between carers and non-carers continues to show when asked about whether they have a long-standing health condition. 53.7% of carers responded that they have a long-standing health condition, compared to 46.5% of non-carers.

When asked about specific medical conditions, it was notable that carers were more likely to suffer from high-blood pressure (28.5%) than non-carers (25.0%) and also more likely to have other non-specified long-term conditions. Nationally, the results are more negative for carers across a broader range of conditions, including arthritis and back problems. For people who provide care for more than 50 hours a week, the results are more negative including a greater likelihood to suffer from angina, asthma, diabetes, and mental health problems and an even higher likelihood for them to have high blood pressure and back problems.

Carers under WAM CCG were more likely than non-carers to suffer from pain/discomfort and anxiety/depression. Half of carers (50.0%) said they have slight to extreme pain/discomfort, compared to 39.9% of non-carers. 29.3% of carers said they are slightly to extremely anxious/depressed, compared to 27.3% of non-carers. This rises to 35.8% for people who provide more than 50 hours of care per week.

Please note there are also 3 GP practices in the BAA CCG region.
5. Carers’ assessments and carers known to local services

This section sets out evidence to help us understand
- Information on carers’ assessments and self-directed support
- The makeup of carers who have had an assessment in RBWM
- The young carers and parent carers who are in touch with services
- Comparisons between national and local data on carers to identify ‘hidden carer’ groups

5.1 Introduction

We have seen that there is some strong evidence on carer numbers and makeup in RBWM based on national datasets, in particular, the Census. The Census is the only consistent measure of carer numbers nationwide and provides a robust benchmark to use when analysing the reach of local services.

This chapter provides information about the carers’ assessment and self-directed support process and analyses some of the detailed data collected by Adult Social Care and local carers’ support services, including the makeup and location of known carers.

5.2 Carers’ assessments and self-directed support

5.2.1 Carers’ assessments: the law

Social services departments have a general duty to assess carers, when requested to do so. The right to a carers’ assessment is triggered once a carer has requested that one take place. This should be carried out as soon as reasonably practical or immediately in an urgent case.

There is also a duty on local authorities to inform carers of their right to a carers’ assessment where they believe the carer provides or intends to provide a substantial amount of care on a regular basis.

These duties will be changing under the Care Bill, which is expected to receive royal assent in 2015. The Bill places a duty on local authorities to assess a carer and removes the requirement for the carer to ask for an assessment. It also removes the requirement for the carer to be providing regular and substantial care.

The new legislation requires for the first time that the assessment determines whether the adult or carer has needs and whether those needs meet set eligibility criteria. An ‘eligible’ need is defined as one that a local authority has a duty to meet. There will be some
needs which are not deemed ‘eligible’ for which the local authority will not be under a duty to meet. It is not yet clear at what level the threshold will be set.46

There can be many outcomes from a carers’ assessment. It should help carers feel that they and the role they play are recognised and valued. It should also provide assessors and/or other support workers with an opportunity to effectively advise carers on information and support services that are available to them, based on the needs and aspirations identified in the assessment.47

5.2.2 Joint and separate assessments
Carers can choose between a separate assessment of their needs and a joint assessment with the person they care for. Figure 29 on Page 56 shows how many carers’ assessments or reviews have taken place in RBWM each financial year since 2005/6. This shows a falling number of carers’ assessments since 2009/10, with the lowest result in 2012/13 (595 carers). This is counterintuitive to the rising numbers of carers identified by the Census, in particular those providing high intensity care who are more likely to need support.

The balance of separate to joint assessments shows 39.5% of assessments in 2012/13 being carried out jointly with the service user. Compared to the number of service users receiving community-based services (see 3.4.1 Adult Social Care), this implies that around a quarter (25.1%) of service users had a carer who received an assessment in 2012/13.

Figure 30 on Page 56 shows the number of carers’ assessments per 100,000 total population for RBWM and its comparator group councils. This shows that RBWM is performing below average compared to comparators.

5.2.3 Services following an assessment
Following an assessment or review, carers may receive a service and/or information and advice. This could be a care package that includes respite or a carer’s break, or they may be signposted to universal services such as those offered by Berkshire Carers, or referred to other groups and services that support carers.

Figure 31 on Page 57 shows how many carers received services or information following an assessment or review for each financial year since 2005/6. As with the carers’ assessments chart above, performance has been falling since 2009/10 with the lowest result in 2012/13.

The figure also shows that in 2012/13, 57.1% of carers received information only following an assessment. The balance of services to information only following a carer’s assessment has been becoming more level since 2009/10. The definition of information and advice is that it should be person centred and specifically tailored to the individual needs of the carer.48

46 http://www.carersuk.org/professionals/resources/briefings/item/2648-draft-care-and-support-bill-briefing
48 Referrals, Assessments and Packages of Care (RAP) Guidance (HSCIC, 2013/14)
Figure 32 on Page 57 shows the number of carers who have received services and/or information and advice following an assessment or review, per 100,000 total population for RBWM and its comparator group councils. This shows that RBWM is performing below average; in terms of the balance between services and information only provision, it is somewhere in the middle compared to Cheshire East which provides very low numbers of services following assessment (1.9%), and Reading which provides services following just under two thirds of their assessments (63.2%).

Some carers may be receiving support outside of a statutory assessment, through universal support services such as Berkshire Carers. However, it has not been possible to secure data from the service to demonstrate this.

5.2.4 Self-directed support and direct payments
Direct payments are monetary payments made by councils directly to service users and carers who have been assessed as needing services. The person who receives the payment must have control over how services are delivered.

Self-directed support means that people are able to design the support and care arrangements that best suit their specific needs. Individuals have a personal budget which is a notional amount of social care funding that can be taken as a direct payment, or services can be arranged for and paid by the council.

Figure 33 on Page 58 shows that, despite moving to a self-directed support process in 2011/12, the number of carers receiving this fell dramatically in 2012/13.

Figure 34 on Page 58 shows RBWM’s performance against its comparators in terms of numbers of carers receiving self-directed support and/or direct payments. RBWM’s performance is well below average compared to comparators. The national and regional result overlaps (245 per 100,000 pop).
Figure 29

Joint and separate carers' assessments and reviews in RBWM; Source: NASCIS

Figure 30

Joint and separate carers' assessments and reviews in RBWM and comparator group councils 2012/13; Source: NASCIS
Figure 31

Carers receiving services or information following an assessment or review; Source: NASCIS

Figure 32

Carers receiving services or information following an assessment or review in RBWM and comparator group councils 2012/13; Source: NASCIS
Figure 33

Number of carers receiving self-directed support and/or direct payments; Source: NASCIS

Figure 34

Carers receiving self-directed support and/or direct payments in RBWM and comparator group councils 2012/13; Source: NASCIS
5.3 Adult carers known to RBWM

Figure 35 on the next page shows the age and gender breakdown of 460 carers known to RBWM who received an assessment or reassessment of their needs between January and December 2013. This shows that the known carers are predominantly female (71.0%) and aged 65 and over (55.5%).

Compared to Census results, known carers are far more likely to be female and aged 65 and over. A quarter (24.1%) of adult carers identified by the Census are aged 65 and over and 57.4% are female.

Data is collected on the ethnicity of most carers; 5.9% do not have this information recorded. Figure 36 on the next page shows that 13.2% of those who do have their ethnicity recorded are from BME groups. This compares to 16.7% of carers identified by the 2011 Census as being from BME groups. The largest ethnic group after White British (86.8%) is White Other (3.5%), followed by Indian (3.0%) and Pakistani (1.8%). There are low numbers of carers from BME groups represented in the local data, implying there are hidden carers within those communities in RBWM.

Almost three quarters (72.8%) of the known carers in RBWM have a postcode recorded. More than 9 out of 10 carers who received an assessment or reassessment in 2013 lived in RBWM (96.1%). Of those carers, the highest numbers are in Oldfield (7.9%), Clewer North (7.9%) and Hurley and Walthams (7.6%) and the fewest are in Eton and Castle (0.6%), Eton Wick (1.6%) and Park (1.6%).

Map 4 on Page 61 shows the location of those carers in RBWM, against the number of carers in each Lower Super Output Area (LSOA). The known carers are marked with a dot which gets bigger depending on the number of carers at a particular postcode. This shows large clusters of carers in Oldfield and Clewer North; however, it shows fewer known carers in some of the areas that the Census identifies as having more densely populated carer populations, such as Bisham and Cookham and Sunninghill and South Ascot.

There are larger clusters of known carers around areas with high concentrations of social housing including parts of Hurley and Walthams, Pinkneys Green and Oldfield.

Compared to Census results, known carers are far more likely to be female, White British and aged 65 and over.
Figure 35

Age and gender of carers known to social care; Source: RBWM

Figure 36

Ethnicity of carers known to social care; Source: RBWM
Map 4

Map of RBWM showing the location of known carers against the number of carers in each LSOA; Source: RBWM and Census (2011)

Contains Ordnance Survey data © Crown copyright and database right 2014
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Figure 37 below shows the percentage of higher intensity carers in each ward who received an assessment in 2013. This is based upon Census data for numbers of people aged 16 and over who provide unpaid care for 20 or more hours per week, and local social care data on the numbers of carers who have had an assessment from adult social care.

This is not an exact science, but it does imply that identification of carers in areas such as Hurley and Walthams and Bray is much better than in Park and Sunninghill and South Ascot.

Service users are allocated an overarching client group which reflects their primary need. These are

- **Physical disability** – a wide category which encompasses physically frail people and those with illness or incapacity, including sensory impairment
- **Mental health** – including adults with mental health conditions, and those with dementia
- **Learning disability**
- **Substance misuse** – those with drug and/or alcohol related problems
- **Other vulnerable people** – includes those whose situation cannot be appropriately fitted in any of the other groups

Percentage of carers aged 16+ providing 20 or more hours of unpaid care per week identified by the Census who have had an assessment in 2013; Source: RBWM and Census (2011)
More than a third of the carers (36.1%) do not have this information recorded, but for those that do, Figure 38 below shows that more than half of the service users being cared for have a physical disability (51.4%). A quarter (24.5%) have a mental health condition and 8.2% have a learning disability. There are low numbers of service users recorded as having an overarching client group of ‘substance misuse’ or ‘other vulnerable people’.

The figure also shows that more than two thirds of service users (68.0%) are aged 65 and over.

**Figure 38**

5.4 Adult carers known to Berkshire Carers

Data was requested but none was received from Berkshire Carers.

5.5 Young carers known to Family Action

Family Action delivers support to young carers across England, and has a service in RBWM that supports young carers across the borough. The service works directly with young people and their families to support them in their caring role and with having a life outside of caring, including school and leisure activities.

Referrals to the service come mostly from children’s social care; very few referrals currently come from schools or mental health services. Most referrals are for young carers in the Maidenhead area, with some in Windsor but none currently in Ascot.
At first point of contact, Family Action will collect some details about the young person and their family situation, and will usually visit the family to find out more about what is needed and to carry out a young carer's assessment. A support plan can then be agreed and suitable interventions offered, including 1:1 support and regular clubs and social activities.

The young carers are assessed using the MACA and PANOC systems. MACA provides an overall summary score for the amount of caring activity provided – from none to very high – for different sub-areas including personal care, domestic tasks, emotional care and sibling care. PANOC measures the subjective cognitive and emotional impacts of caring and provides a score based on the positive and negative impacts. These scores can indicate areas of concern and where greater support may be required.

A RAG (red, amber, green) rating is also given to each young carer depending on the level and impact of their caring role, and Family Action will work with the young people and their families to improve this rating. A red or amber rating may also indicate where there is a child protection issue or where intensive family support is currently in place.

As at February 2014, Family Action is working with 57 young carers and generally has an active caseload of between 60 and 70 young people. Figure 39 on the next page shows that more than half (56.1%) of these 57 carers are aged 5-12 and 43.9% are aged 13-18. 4 in 10 (42.1%) of the carers are girls and 6 in 10 (57.9%) are boys.

Almost three quarters of the young carers have a White British background (73.7%) and 21.1% are from Asian groups. The other ethnic groups represented are Mixed White and Asian (1.8%) and White Other (3.5%).

The young carers come from across the borough; however, some areas such as Ascot and Cheapside, Sunninghill and South Ascot and Sunningdale are not represented. The highest concentrations are in areas around Maidenhead, with just over a third of the carers living in Belmont (17.5%) and Oldfield (17.5%).

Schools attended by the young carers include 22 in RBWM, 2 in Buckinghamshire and 1 in Slough. Some schools, such as Altwood Church of England School (8 young carers) and Newlands Girls’ School (6 young carers), have more young carers identified than others. There are more than 60 schools in RBWM so many are not currently represented.

Figure 40 on the next page shows the conditions being supported by the young carers known to Family Action. This shows that 4 in 10 (41.7%) of the carers are supporting physical health/disabilities. 3 in 10 (27.8%) are supporting mental health problems and 3 in 10 (27.8%) are supporting learning disabilities. More than half of the carers (54.2%) are supporting a parent and the largest groups supported are parental physical health/disability (20 carers) and sibling learning disability (18 carers).

11 of the carers are supporting more than one condition (e.g. Learning Disability and Mental Health) and 3 are supporting more than one family member (e.g. sibling and parental).
Figure 39

Age and gender of young carers known to the Family Action service; Source: Family Action

Figure 40

Conditions being supported by the young carers known to Family Action; Source: Family Action
Figures 41 and 42 below show the level of intensity of the caring role and the level of impact that the caring role has on the young person. These show that 43.9% of the young carers have a caring role that is considered to be medium to high intensity and 38.6% have a caring role that impacts on their life at a medium to high level.

**Figure 41**

![Level of intensity of the young carers’ caring role; Source: Family Action](image)

**Figure 42**

![Level of impact of the young carers’ caring role; Source: Family Action](image)
5.6 Parent carers known to Children & Young People Service, RBWM

Until 2014, the Learning Difficulties and Disabilities (LDD) Service worked with families who have a young person aged 0-18 with a physical or sensory impairment, or learning difficulty/disability, which has a substantial and long term impact on them carrying out day to day activities.

Figure 43 on the next page shows the number of parent carers’ assessments carried out by the team over the past decade. This shows a fluctuating picture with peaks in 2010 (36 assessments) and 2012 (36 assessments). However, the number of assessments fell by more than half in 2013 (15 assessments). The explanation for this is not entirely clear but could be that carers are satisfied and feel that services are meeting their needs.

Following a restructure of Children’s Services in 2014, the new Children & Young People Disability Service (CYPDS) has been created bringing together the former LDD Service, the Special Education Needs (SEN) Team and the Berkshire Sensory Consortium Service. This new service aims to streamline the assessment and administration processes, ensuring that services are more responsive and joined up and that the journey of the child and family is positive. It also allows the local authority to meet and implement the requirements of the Children and Families Act.

CYPDS regularly consults with children, young people and their families to ensure services are actively shaped by them. These include annual feedback forms, an electronic consultation group and an informal ‘Parents Share Group’. Parent Information Sessions are also run regularly to support parents, including topics that they have chosen themselves, such as welfare benefits, sleep awareness and promoting positive behaviour.

As at November 2013, data from the former LDD Service shows that 329 children and young people were supported. 49 21.9% were aged 0-4, 38.0% aged 5-12 and 40.1% aged 13-18. Almost a quarter (23.7%) were from a non-White background. Figure 44 on the next page shows that Autism/Autism Spectrum Disorder (ASD) is the most common primary need supported by families (44.4%), followed by Learning Disability (12.8%) and Physical Disability (9.7%).

Short break services are provided including day care and overnight care in the child’s home or elsewhere, and a range of activities for children and young people and their families such as Saturday clubs, school holiday activities, youth clubs and leisure centre activities. Short breaks can provide opportunities for children and young people to spend time away from their families and have fun, and also provide respite for families, giving them a break from their caring responsibilities. Families may also be able to take part in activities together. Direct Payments are also available to fund breaks.

6 in 10 of the children and young people supported by the LDD Service (61.1%) access regular short breaks, providing respite for their families. Children and young people

49 Data in future years will reflect the wider cohort of all children and young people known to CYPDS
people aged 5-12 are most likely to access short breaks (58.7%), followed by those aged 13-18 (34.8%).

**Figure 43**

Parent carers’ assessments in RBWM; Source: RBWM

**Figure 44**

Primary needs breakdown for the children and young people supported by the LDD Service; Source: Children and Young People Disability Service, RBWM
5.7 Carers known to GP practices

There are over 20 GP practices in the WAM CCG region and they keep a register of their patients who are also carers. Registering carers can help GPs to better understand the condition of the person being cared for and to keep a closer eye on health problems that are more common amongst carers.

9 of the practice managers returned details of the carers registered with their practice and those which had had an NHS Health Check. Table 5 below shows low numbers of registered carers and low numbers of carers having NHS Health Checks (where data was available).

Table 5

<table>
<thead>
<tr>
<th>Practice name</th>
<th>Practice postcode</th>
<th>Carers</th>
<th>Carers with an NHS Health Check</th>
</tr>
</thead>
<tbody>
<tr>
<td>Claremont Surgery</td>
<td>SL6 8AN</td>
<td>35</td>
<td>Unknown</td>
</tr>
<tr>
<td>Cookham Medical Centre</td>
<td>SL6 9HX</td>
<td>7</td>
<td>0</td>
</tr>
<tr>
<td>Holyport Surgery</td>
<td>SL6 2LP</td>
<td>7</td>
<td>Unknown</td>
</tr>
<tr>
<td>Radnor House Surgery</td>
<td>SL5 7EN</td>
<td>27</td>
<td>0</td>
</tr>
<tr>
<td>Redwood House Surgery</td>
<td>SL6 3PH</td>
<td>33</td>
<td>Unknown</td>
</tr>
<tr>
<td>South Meadow &amp; Dedworth</td>
<td>SL4 6AP &amp; SL4 5JL</td>
<td>111</td>
<td>Not currently offered by practice</td>
</tr>
<tr>
<td>Taplow Health Centre</td>
<td>SL6 0PD</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>The Symons Medical Centre</td>
<td>SL6 6EL</td>
<td>30</td>
<td>18</td>
</tr>
<tr>
<td>Woodlands Park Surgery</td>
<td>SL6 3NW</td>
<td>10</td>
<td>3</td>
</tr>
</tbody>
</table>

Carers registered with GP practices in the WAM CCG region; Source: GP Practice Managers

NHS Health Checks are a chance to assess someone’s risk of heart disease, stroke, kidney disease, diabetes and dementia, through straightforward tests and questions about lifestyle and medical history. These are generally offered every five years to people aged between 40 and 74. Some local authority areas offer health checks more widely and frequently to carers due to the increased health impacts associated with their caring role.

Please note there are also 3 GP practices in the BAA CCG region who were not contacted for this project.
6. Key findings

This section sets out the key findings of the evidence base collection to
- Inform the development of the new joint carers’ strategy in RBWM
- Help prepare for the changes in the Care Bill and Children and Families Act

6.1 Key findings from the evidence base collection

6.1.1 The demand for care
- The older population aged 65 and over is growing exponentially and is projected to increase by 19% in RBWM by 2021, placing a much greater strain on health and social care services
- The largest older populations are in Clewer North, Bisham and Cookham and Oldfield; however, health outcomes in Bisham and Cookham are better
- Clewer North and Oldfield have areas of higher deprivation with more people living in social housing, poor health outcomes for older people, a high proportion of older people living alone and high numbers of adults claiming DLA
- Clewer East and Clewer South have the poorest health outcomes, particularly for older people, as a well as a high proportion of older people living alone and high concentrations of people living in social housing
- There are lower numbers of older people in Eton Wick, but a high proportion of the population are older and they have poor health outcomes, with almost 4 in 10 living alone
- Boyn Hill has the largest BME population and some of the highest levels of deprivation in RBWM
- Number of adults receiving social care support has been falling, in spite of evidence of increasing demand for care; however, the number of children receiving statutory support has been steadier
- There are rising numbers of emergency admissions to hospital
- Less people die in hospital and more people die in a care home than the England average
- The Berkshire area scores average to low in terms of carers being supported at the end of their loved one’s life
- There are a rising number of people claiming DLA
- Despite growing numbers of older people with poor health outcomes, claims for Attendance Allowance have fallen in the past year

6.1.2 The availability, makeup and experiences of carers
- There are 13,125 carers in RBWM; 9.2% of the population
- The largest proportion of carers is in Bisham and Cookham (10.8%) but the largest carer population is in Clewer North (776 people)
- 1 in 5 people aged 50 to 64 are providing unpaid care and females are more likely to be high intensity carers than males
- There are large numbers of carers from Other White, Indian and Pakistani groups and there are likely to be hidden carers within these groups.
- Carers are more likely to have poor health outcomes than non-carers, particularly older carers and those caring for more than 20 and 50 hours per week.
- High intensity carers are more likely to suffer from a range of health conditions including angina, diabetes, high blood pressure, back problems and mental health problems.
- Clewer North has the largest population of carers and older carers with poor health outcomes, and the largest population of people providing 50 or more hours of unpaid care per week.
- Furze Platt, Oldfield and Boyn Hill also have large populations of carers with poor health outcomes, and high numbers of people providing 50 or more hours of unpaid care per week.
- More than 1,200 people aged 65 and over are providing more than 20 hours of unpaid care per week and this is likely to be a group with high needs.
- Carers are more likely than non-carers to be in part-time work, but those providing more than 20 hours of unpaid care per week are far less likely than non-carers to be in employment.
- A quarter of carers in paid employment said they did not feel supported in their caring role by their employer.
- The number of carers claiming Carer's Allowance has been rising year-on-year but there are still almost 400 carers that are missing out.
- There are 225 carers aged under 16 and 525 aged 16-24 identified by the Census, though research suggests this is likely to be an underestimate.
- Young carers are 2.6 times more likely to report their health as 'not good' compared to other young people.
- Census data implies there are higher numbers of parent carers in Furze Platt, Belmont, Bisham and Cookham, Oldfield and Boyn Hill.
- Carers in RBWM report that they are not able to spend as much time as they'd want doing the things they enjoy, including social contact with people they like.

6.1.3 Carers’ assessments and carers known to local services
- In spite of rising numbers of carers identified by the Census, the number of carers’ assessments has been falling since 2009/10 with the lowest result in 2012/13 and low performance against comparator councils.
- The number of carers receiving a service or information and advice following assessments has similarly been falling.
- The number of carers receiving self-directed support and direct payments was low in 2012/13 and very low against comparator councils.
• By comparison with Census results, carers receiving a social care assessment are more likely to be female, White British and aged 65 and over
• There are larger clusters of known carers around areas with high concentrations of social housing including parts of Hurley and Walthams, Pinkneys Green and Oldfield
• Carers who have had an assessment are most likely to be caring for someone older with a physical disability
• Carer identification appears to be better in some areas of RBWM such as Hurley and Walthams and Bray; it is not so good in Park and Sunninghill and Ascot
• More than half of the young carers that are engaged with Family Action are boys and more than half are aged 5-12
• Young carers are most likely to be caring for a parent and are supporting a range of disabilities including physical health, mental health and learning disabilities
• Carers have been identified in around a third of the schools in RBWM; however, in most schools there are low numbers
• Young carers known to Family Action are predominantly located in areas around Maidenhead, with less known in areas around Ascot, Sunninghill and Sunningdale
• Parent carers known to RBWM are supporting children of all ages and are supporting a range of disabilities, but the most common is Autism/Autism Spectrum Disorder
• 6 in 10 of the children and young people being supported access short breaks
• GP carer registers show low numbers of carers registered in most cases and very low numbers of carers receiving an NHS Health Check

6.2 Preparing for the Care Bill and Children and Families Act

The Care Bill and Children and Families Act present significant opportunities to improve support for carers by consolidating existing legislation, harmonising rights for all carers, and integrating care and support with health.

This evidence base collection has highlighted some key areas that require further development so that RBWM are fully prepared for the new Bills. Qualitative evidence from the consultation process will also highlight relevant areas for development and should be considered alongside this quantitative evidence.

6.2.1 Integrating care and support with health

RBWM are already leading on integrating carers’ support across health and social care by jointly developing a new carers’ strategy for the borough that intends to improve the health and wellbeing of carers and the quality and diversity of services to support them.

Health and social care should also be working together with providers, service users and carers to plan for spending the Better Care Fund. Nationally, the fund includes £130m of carers’ breaks funding.
6.2.2 Current and future demand for care
Councils have a responsibility to understand current and likely future demand for care. Nationally, evidence points to a growing demand for care due to an ageing population and an increased prevalence of long-term conditions. Areas with high populations of older people – particularly those showing poor health outcomes – are likely to see increasing needs as people age.

Local authorities need to consider the capacity of families to continue providing care as part of their thinking about future demand. A small shift in the number of people providing care could have a massive impact on health and social care services.

Areas of RBWM with higher numbers of older people generally have more carers and these carers are more likely to be aged 65 and over, providing the highest intensity caring and have poor health outcomes. Caring roles in those areas are likely to be at increased risk of breakdown, which leads to a heavy strain on resources. Support should be targeted at areas including Clewer North, Furze Platt, Oldfield, Boyn Hill, Maidenhead Riverside and Pinkneys Green to reduce needs amongst the ageing population and the carers with poor health outcomes, and to try to prevent or delay the development of future needs. Some areas have smaller numbers, but high concentrations of older carers with poor health outcomes, including Eton Wick, Clewer East, Belmont and Clewer South. The Council could work with its partners including the voluntary sector to support older carers.

6.2.3 Health and wellbeing
The Care Bill places a duty on local authorities to promote the wellbeing of carers – including their physical and mental health – and local authorities must work with health providers to do this if necessary. Carers receiving services in RBWM report poor wellbeing outcomes, including lack of social contact and not enough control over their daily life.

Carers may benefit from further service interventions that promote their health and wellbeing, including breaks and social activities. Personal budgets and direct payments can have a positive impact on carers’ lives, but the number of carers receiving them in RBWM is very low.

Carers also report poorer health outcomes than non-carers and in particular, high intensity carers are more likely to suffer from a range of health conditions including high blood pressure and mental health problems. These are also issues that the local authority could work with health and public health partners to target support to prevent, delay or reduce needs. Carers in areas with poor health outcomes could be targeted for NHS Health Checks for example. The number of carers identified by GPs and offered NHS Health Checks is low.

6.2.4 Prevention, early intervention and unmet need
The Care Bill states that local authorities have a duty to provide or arrange services that will prevent, delay or reduce the need for care and support by carers. Part of this involves identifying carers with unmet needs and targeting interventions to support them before their situations get to crisis point.

Evidence on the makeup of carers receiving social care support implies that male carers, BME carers and working age carers are less likely to be
accessing support and could benefit from some targeted interventions. Evidence also points to hidden carers within LGBT groups and some religious communities.

Male carers are generally prevalent in all areas of RBWM, so borough-wide awareness raising would be appropriate. BME carers are also present in all areas, but a targeted approach, perhaps via community groups, may be more appropriate in areas with larger BME carer communities, including Maidenhead Riverside, Boyn Hill, Belmont and Oldfield.

There is a higher concentration of working age carers in areas including Castle Without, Eton and Castle, Clewer East, Belmont, Datchet and Eton Wick. The Care Bill states that local authorities must consider how they will support carers to participate in work, education or training if the carers wish to. The National Carers Survey also highlighted a quarter of carers in work in RBWM who do not feel supported by their employer. Working age carers would benefit from flexible support services that enable them to work and train alongside their caring role. RBWM might like to consider membership of Employers for Carers, which provides advice and support to employers seeking to develop carer friendly policy and practice and retain skilled workers.50

6.2.5 Information and advice
The Care Bill places a duty on local authorities to establish and maintain a service for providing local people with information and advice relating to care and support for adults and support for carers. This must include information on how to access independent financial advice on matters related to meeting care and support needs, the local authority should identify adults who would be likely to benefit from financial advice in this regard.

Research has shown there are huge pressures on carers’ finances due to reducing support from benefits and social care. The number of carers receiving services in RBWM has been falling in recent years, and almost 400 carers who could be claiming Carer's Allowance are missing out. Carers are a group in RBWM that could benefit from advice about financial support and automatic benefits checks. RBWM could target promotion of Carer's Allowance in areas where carers are more likely to be eligible due to the level of their caring role, such as Clewer North, Oldfield and Belmont.

6.2.6 Carers’ assessments and a whole family approach
The Care Bill extends adult carers’ rights to assessment by removing the need for a carer to request an assessment and the need for them to be providing ‘regular and substantial care’.

For the first time, local authorities have a duty to assess carers’ eligible needs and provide them with support and services to meet those needs.

In RBWM, the number of carers receiving an assessment or reassessment of their needs has been falling. Just over a quarter of social care service users have a carer who has received an assessment. Under the Care Bill, more carers will be eligible for assessment, and assessments will be important in terms of fully understanding a carer’s current and likely future health and social care needs, to avoid them deteriorating and to avert carer breakdown.

50 https://www.employersforcarers.org/
Carers’ assessments should have regard to the needs of the whole family and in particular it will be important to identify young carers in the family in line with their new rights as part of the Children and Families Act. Likewise, when young carers are identified, it should trigger an assessment of need for the person they are caring for. This will require protocols to be developed or refreshed between adults and children’s services in RBWM.

The new Bills introduce new considerations about transitions e.g. when young carers turn 18, or when a child being cared for turns 18. Young carers and parent carers should be assessed in these situations if they are likely to continue to have support needs. Again, this will require appropriate protocols to be in place between children’s and adults services.

Currently young carers are referred to Family Action and it works with around 60 to 70 carers at a time. The Census identified many more young people with caring responsibilities in RBWM – and there are likely to be even more – so more proactive work is needed, including work with schools, to identify and support young carers.

New and strengthened rights for parent carers to assessment will also impact on demand. As with other carers, parent carers will no longer be required to provide ‘regular and substantial care’ and local authorities must carry out an assessment on appearance of need, as well as following a request. The number of recorded parent carer assessments in RBWM is currently low by comparison to implied demand.

Councils will have powers to delegate assessment functions to cope with increased demand, including decisions on eligibility; however, they still have legal responsibility for delegated functions.

RBWM may also want to consider training for practitioners to ensure they are aware and prepared for the changes to practice that the Care Bill and Children and Families Act present, including new assessment and eligibility duties.

It is recommended that RBWM carry out a more detailed review of their carer’s assessment processes and recording and reporting protocols across adults and children’s services, to align assessments for adult carers, young carers and parent carers. All three groups of carers should be covered by the new joint Carers’ Strategy.

6.2.7 Market shaping
The Care Bill places a duty on local authorities to promote the efficient and effective operation of a market in services for meeting the support needs of carers. There should be a variety of providers and high quality services to choose from, and sufficient information available for people to make an informed decision about how their needs will be met. This duty should also have regard to supporting carers to participate in work, education or training, and promoting their wellbeing.

RBWM should fully digest this evidence base, alongside the qualitative evidence collected as part of the carers’ strategy consultation, and use it to direct their approach to market shaping.