

**NHS** BRACKNELL AND ASCOT  
*Windsor, Ascot and Maidenhead* CLINICAL COMMISSIONING  
*Clinical Commissioning Group* GROUP

# **Integrated Commissioning Strategy and Delivery Plan 2014 -2017**

## **Carers**

**Contents**

| <b>Section</b> |                                      | <b>Page No</b> |
|----------------|--------------------------------------|----------------|
| <b>1.</b>      | Executive Summary                    | <b>3</b>       |
| <b>2.</b>      | Introduction                         | <b>4</b>       |
| <b>3.</b>      | Who is a carer                       | <b>5</b>       |
| <b>4.</b>      | Our Vision                           | <b>5</b>       |
| <b>5.</b>      | Model of Support                     | <b>7</b>       |
| <b>6.</b>      | Background and Context               | <b>8</b>       |
| <b>7.</b>      | What do we know about carers in RBWM | <b>10</b>      |
| <b>8.</b>      | Experiences of caring                | <b>11</b>      |
| <b>9.</b>      | Impact of caring                     | <b>15</b>      |
| <b>10.</b>     | Supporting carers in RBWM            | <b>22</b>      |
| <b>11.</b>     | Other areas of work                  | <b>23</b>      |
| <b>12.</b>     | Delivery Plan                        | <b>24</b>      |
| <b>13.</b>     | Monitoring progress                  | <b>32</b>      |
| <b>14.</b>     | Appendices                           | <b>33</b>      |

## 1. Executive Summary

1.1 A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. By caring for people in their own time and supporting other people's independence, carers embody the spirit of the Big Society.

1.3 In the UK, more than 6.5 million people care, unpaid, for friends or family members who are ill, frail or disabled. Approximately 13,125 people have identified themselves as Carers in RBWM in the 2011 Census, and this is likely to be an underestimate of the true numbers of people caring. This number has increased by 15.1% since 2001 – which is much faster than the rise in the overall population (8.2%). Carers make up 9.2% of the total population in RBWM. 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.

1.4 27.4% of carers in RBWM provide care for more than 20 hours per week and 16.6% of carers provide care for more than 50 hours per week. Whilst there is a varied age profile of carers in the borough as the caring role gets more intensive, the proportion of older carers increases.

1.5 The impacts of caring span across numerous aspects of the carers' life including their health and well-being, ability to gain and maintain employment or educational achievement and therefore has a longer term impact on the finances of the carer. In addition, caring can have a significant impact on the ability to have a life outside of caring which can lead to feelings of social isolation and also depression.

1.6 Locally a number of services are available to support carers to continue in their caring role through the voluntary sector, in house services and also contracted services. This enables many residents in need of care and support to remain living in their own homes for longer and a part of their local community. Carers should be supported as individuals and in their families and communities to help shape, develop and run local services, if they wish to be involved.

1.7 Supporting carers is a vital part of delivering the prevention agenda due to the role they play in maintaining the health and independence of the person they care for and therefore preventing the need for services. It is essential therefore that carers receive support themselves.

1.8 The Carers Strategy has identified seven priorities:

**Priority 1:** Carers are able to access to information, advice and support

**Priority 2:** Improve carers experience of navigating the services available

**Priority 3:** Support carers to access opportunities to take a break from caring

**Priority 4:** Increase carer identification

**Priority 5:** Improve the health and well-being of carers

**Priority 6:** Help carers fulfil their education, employment and life chances potential

**Priority 7:** Ensure that carers support is targeted and reaches the diverse communities in the borough

1.9 The delivery plan associated with this strategy sets out the plans and commissioning intentions for how services will be designed and delivered to and with carers across RBWM over the next three years to deliver these priorities. It will provide an integrated approach to commissioning across adult social care, children and families and health.

## **2. Introduction**

2.1 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 are estimated to save the state £119 billion per year. The care that they provide to help sustain people in their own homes and in their own communities is vital, embodying the Big Society agenda.

2.2 This integrated commissioning strategy for carers is an over-arching strategy and delivery plan agreed by RBWM, WAM CCG and BA CCG in relation to supporting carers in our community and how we will work with a range of our local partners, particularly in the voluntary sector, to deliver this support. It has been developed with carers, NHS and voluntary/community sector partners.

2.3 This strategy is intended to support carers by responding to their needs and improving services recognising the crucial role which carers play in the life of the person they care for, the support they require to continue carrying out this role as well as their need for a life outside of caring.

2.4 It is vital that carers receive support themselves, as the role of being a carer can be challenging and demanding as well as rewarding. Negotiating the network of services and information involved, actually providing the care and support as well as maintaining their own health and well-being can all add to the stresses a carer may experience. Care Bank is an excellent example of how carers can be supported further through the use of local volunteers.

2.5 The joint Health and Well-being strategy 2013 (a joint strategy across RBWM, WAM CCG and BA CCG) sets out the overarching themes where the Health and Well-Being board should focus its attention, including carers. These are:

## Carers Strategy 2014-2017

- Supporting a Healthy Population
- Prevention and Early Intervention
- Enable Residents to Maximise their Capabilities and Life Chances

More specifically it recognises that services for carers are essential to support carers to manage and live well with their caring role. With a commitment to ensuring they have the correct information they need, including them with the service planning for the person they are caring for and their satisfaction with services. In addition, support to carers and enabling them to stay healthy and well is identified as a key priority in the Prevention and Enablement strategy (2014-17).

2.6 It must meet the demands of both the Care Act and address the wider strategic priorities of health and social care. 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 2014.

2.7 The strategy includes a detailed delivery plan to meet the priorities identified. This plan will be updated annually and published on both the RBWM and WAM CCG websites.

### **3. Who is a carer?**

A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support.

Young carers are children and young people under the age of 19 who provide or intend to provide care, assistance or support to another family member who is disabled, physically or mentally ill, or has a substance misuse problem.

### **4. Our vision for all carers in the Royal Borough of Windsor and Maidenhead**

Following the variety of information and feedback collected from local carers this strategy establishes the following priorities and outcomes for local carers up to 2017:

**Priority 1: Carers to have access to information, advice and support**

**Priority 2: Improve carers experience of navigating the services available**

**Priority 3: Support carers to access opportunities to take a break from caring**

**Priority 4: Increase carer identification**

## **Carers Strategy 2014-2017**

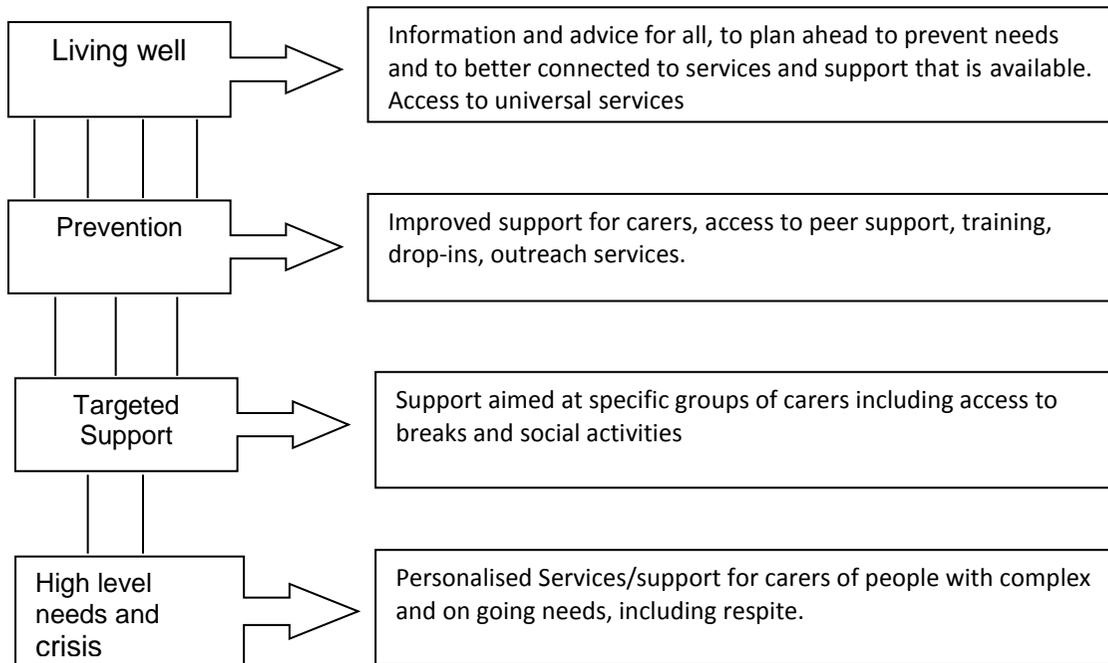
**Priority 5: Improve the health and well-being of carers**

**Priority 6: Help carers fulfil their education, employment and life chances potential**

**Priority 7: Ensure that carers support is targeted and reaches the diverse communities in the borough**

**5. Model of support**

The diagram below illustrates the need for the Carers Strategy to outline a clear vision and actions to support carers at each level, from universal services through to crisis response. It is anticipated that the voluntary and community sector as well as the range of universal services in place have a large role to play in the first two stages of support – Living Well and Prevention, whilst the latter two stages are areas where RBWM are likely to play a role in supporting carers. This is aligned to the Early Help model of support in Children’s services.



## 6. Background and Context

### 6.1 National Carers Strategy

In November 2010 the government published *Recognised, valued and supported: next steps for the Carers Strategy*. This sets out the national vision and outcomes to be achieved for carers:

#### **Vision:**

*“Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen”.*

The following outcomes were identified as priority outcomes areas:

- Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.
- Carers will be able to have a life of their own alongside their caring role.
- Carers will be supported so that they are not forced into financial hardship by their caring role.
- Carers will be supported to stay mentally and physically well and treated with dignity.
- Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.

These were added to by the Coalition Government in 2010 with further priorities for carers from 2011-15:

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

- Supporting carers to remain mentally and physically well.

### **6.2 Care Act 2014**

The Care Act received Royal Assent on the 14th of May 2014. Part 1 of the new Act consolidates and modernises the framework of social care law. The Care Act brings those funding their own care into the care system with obligations on local authorities relating to information and advice, universal services, assessments and market shaping among others all applying to self-funders. It also sets out a new model of paying for care, putting in place a cap on the care costs which an individual is liable for.

In summary, changes for carers in the Care Act are:

- Carers will have the same legal rights as service users
- Local authorities will have a duty to assess carers who may have eligible needs
- Carers who meet the eligibility criteria will have a right to a support plan and a personal budget
- Carers may be charged for services they receive in their own right
- Carers should be supported to retain and gain employment
- Local authorities will have a duty to provide information and advice and promote well-being.

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

The Government is transforming the system for children and young people with special educational needs (SEN), including those who are disabled, so that services consistently support the best outcomes for them. The Act will extend the SEN system from birth to 25, giving children, young people and their parent's greater control and choice in decisions and ensuring needs are properly met. Young carers' and parent carers' have clearer rights to support from RBWMs. Aligned to the Care Act for adults the law will require local authorities to assess on the appearance of need, as well as following a request by a carer.

There will be a clear read across in both sets of legislation and in local protocols to ensure clarity of approach and clear lines of responsibility.

### **6.4 NHS**

The NHS has acknowledged responsibility to provide support and services for carers as well as for those who are ill. All too often, however, this responsibility to a carer is overshadowed by the immediate clinical needs of the person for whom they care. Without early contact and ongoing support, it is possible for a carer's health or ability to cope to decline unobserved until a crisis point is reached and the care arrangement breaks down. Primary Care Teams, who often have close and regular involvement with people receiving care at home, can play a vital part in supporting carers and thus averting crises.

For most 'informal' carers, the GP surgery is their first point of contact for information, advice and support in their caring role. Research indicates that it is often very modest actions by staff at the surgery that make the difference between carers being able to cope and not being able to continue to care.

### **6.4.1 WAM CCG**

The commissioning plans of WAM CCG for 2014/5 and beyond flow from the joint Health and Wellbeing Strategy within which carers hold a significant, valued and unique role. Working with other health and social care colleagues, WAM CCG is committed to enabling a range of specific activities that will benefit those who themselves need health care, but also singles out those who provide the care and support at home that enable ailing patients to remain independent for longer. Carers form a special group of patients whose health and wellbeing is therefore inextricably linked with that of the family, friends and colleagues who depend upon them. Help one and you help both parties to sustain a balanced existence that avoids crisis – even in difficult and deteriorating situations.

### **6.4.2 Bracknell and Ascot CCG commissioning plan**

BA CCG has identified the following local priorities:

- Improving patient experience
- Management of long term conditions – accessing support from specialist teams quickly
- Heart disease, diabetes and stroke – making healthy lifestyle choices
- Improving mental health

### **6.5 Better Care Fund**

RBWM and WAM CCG have identified a framework for partnership and collaboration known as the Better Care Fund. The key purpose and intention of the Better Care fund is to develop integrated services and better outcomes for local people. Support to carers is a vital part of ensuring that the benefits associated with the fund are delivered. It is well documented that through effective support to carers this can help reduce the number of avoidable hospital admissions as well as the numbers entering residential care.

By 2018 WAM CCG and RBWM want an integrated system – involving a wide range of key partners - that is sustainable for the future with improved outcomes for local people. The changes being planned will result in the following:

- Care being led by the person and involving their family and carers. Conversations should always start with 'what is important to you' and services will come to people.
- Socially isolated people will be encouraged to become more active by the community reaching out to them.

## Carers Strategy 2014-2017

- One point of contact and information sharing between organisations so that people do not have to tell their story more than once and can access information about the right services for them.
- Promote the use of technology to support families, carers and care professionals to work together effectively.
- Supporting older people to remain active, age well and remain fitter for longer through the use of a range of leisure facilities and community events and networks developed with the needs and wishes of older people in service planning.
- Having a comprehensive and responsive spectrum of care available which does not rely on institutional care.
- Recognise everyone desires to be as independent as possible and we will do all we can to support that wherever you live.
- General practice at the heart of local services, directing a range of community and social care services.

### **7. What do we know about carers in RBWM?**

#### **Facts about carers in RBWM**

Carers UK, working in partnership with RBWM and WAM CCG, developed a robust quantitative evidence base on carers drawing on a variety of information sources, including the Census 2011, and has been used to underpin the development of this strategy.

The main findings of the Carers UK evidence report were as follows:

- 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 the 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.
- Clewer North has the largest carer population (776) and Bisham and Cookham has the highest percentage of carers in the population (10.6%).
- 27.4% of carers in RBWM provide care for more than 20 hours per week. 16.6% of carers provide care for more than 50 hours per week. Clewer North not only has the highest number of carers but also highest number providing over 50 hours of care per week.
- There are more female than male carers (57.4% are female).
- The peak age for caring is between 50 and 64 years. As the caring role gets more intensive, the proportion of older carers increases.

## Carers Strategy 2014-2017

- There are 750 young and young adult carers aged under 25, including 225 young carers aged under 16.
- 79.5% of young carers aged under 25 and 82.7% of young carers under 16 years provide unpaid care for 1 to 19 hours per week. 154 young carers aged under 25 were identified as providing more than 20 hours per week.
- In RBWM, the proportion of carers aged 16 and over and in full-time employment is 38.2%, lower than the 48.9% of non-carers aged 16 and over. 17.8% of people who provide care for 50 or more hours are also in full time employment.
- 16.7% of the carer population are from BMW groups. This ranges from 7% of the carer population in Bisham and Cookham to 29.9% of the carer population in Boyn Hill.
- Carers are more likely to report health problems - In RBWM 1 in 5 carers report their health is not good, compared to 1 in 8 non-carers.
- It is estimated that there are 377 carers in RBWM missing out on a total of £1,171,100 Carers Allowance every year.
- In a recent survey, more than two thirds of adult carers in RBWM said they had some social contact but not enough or little social contact and feel isolated.

For more information and the full Carers UK report see [www.rbwm.gov.uk](http://www.rbwm.gov.uk)

### **8. Experiences of caring**

Anyone can become a carer regardless of age, ethnicity or gender and whilst some of the impacts of caring are common to all carers some may experience different impacts and issues to others.

#### **8.1 Young Carers**

8.1.1 Whilst a comparatively small number in comparison to other carer groups the impact of being a young carer can have significant impact on the longer term outcomes for this child or young person.

8.1.2 When practical, emotional or social responsibilities being undertaken by a young carer are inappropriate and/or risk becoming too much to handle there can be significant repercussions on other aspects of their lives. This can include educational development, ability to form friendships or undertake social activities and experiences both in the short term and longer term resulting in young carers not achieving their potential.

- 8.1.3 Young people may have mixed feelings about their caring role. It may give them a sense of value and purpose; however they may also feel frustrated and guilty when it gets in the way of the life that they want to lead. The cumulative impact of worrying about or for a parent or siblings can be especially significant where a parent has mental health, substance misuse or other issues that can create social stigma.
- 8.1.4 The Royal Borough of Windsor and Maidenhead's 2014 -17 Children and Young People's Partnership Plan and the 2013 - 16 Early Help Strategy reinforce their commitment to providing early help or support to children and their families. Through early identification and the provision of the right support at the right time it is acknowledged that the outcomes and chances for children are greatly enhanced.
- 8.1.5 The main area of support for Young Carers is through a specific service that has been commissioned in the third sector and funded by the Local Authority. 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.

### **8.2 Working and working age carers**

- 8.2.1 1 in 9 people in the paid workforce are caring for someone who is ill, frail or who has a disability. Research shows that 45% of carers have given up work because of their caring role and 42% have reduced working hours.<sup>1</sup> Carers who are in employment may need extra support to juggle work and their caring responsibilities.<sup>2</sup> 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.<sup>3</sup>
- 8.2.2 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 to be female and in part-time employment. 17.8% of people who provide care for 50 or more hours per week are also in full time employment and are likely to be a group with high support needs.

### **8.3 Parent Carers**

- 8.3.1 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.
- 8.3.2 The Children and Young People Disability Service supports in the region of 850-900 children and young people with a wide spectrum range of special educational needs, learning difficulties and disabilities. The

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<sup>1</sup> Prepared to Care? (Carers week, 2013)

<sup>2</sup> <https://www.employersforcarers.org>

<sup>3</sup> Sandwich Caring (Carers UK and Employers for Carers, 2012)

## Carers Strategy 2014-2017

service also supports their parents/carers and wider family. Parent carers are caring for children and young people aged 0-18 with a range of conditions, broadly these include:

|   |     |
|---|-----|
| Autistic Spectrum Disorder (ASD)  | 32% |
| Speech, Language Communication Needs (SLCN)   | 18% |
| Moderate Learning Difficulties (MLD)  | 13% |
| Behavioural, Emotional, Social Difficulties (BESD)  | 10% |
| Specific Learning Difficulties (SPLD)   | 9%  |
| Physical Disabilities (PD)  | 6%  |
| Physical & Medical needs (PMED)   | 3%  |
| Profound and Multiple Learning Difficulties (PMLD)  | 3%  |
| Other - Hearing Impairment, Visually Impairment, Severe Learning Difficulties, Multi-Sensory Impairment | 6%  |

The service also holds responsibility for educational needs provision for young people up to the age of 25years.

- 8.3.3 Families with disabled children often face a number of pressures – emotional, financial and practical – and without information and support, can find it difficult to cope and become isolated. Caring for a child with a disability can have a considerable impact on the parent carer and family, siblings and wider family.
- 8.3.4 Some families have more than one child with a disability or learning difficulty. This can bring additional caring duties and stress imposed by having more than one disabled child for parent carers. In the Children & Young People Disability Service approximately 50 families have more than one child with a special educational need and/or disability.
- 8.3.5 The Royal Borough's Commissioning Strategy for Adults with Autism 2012 suggests that the borough has above the national average of school age children with autism. In 2011 28% of statements were for autism whilst a local comparator borough had approximately 20% and a national average of 18.8% in 2010. As at April 2014 The Children & Young People Disability Service suggests that this figure is increasing further with nearly a third of all children in receipt of a statement for autism. Autism is the largest category of statemented need in the borough.
- 8.3.6 Transition may also be a time of change for parent carers. This generally refers to the period from Year 9 (14 years old) to when a young person becomes an adult at age 18 and as they develop through

young adulthood to 25. For the young person, there are opportunities and choices in relation to many areas of adult life. For parents and carers there is a need to adjust to the practical and emotional changes as their young person becomes more independent. For both the young person and the parent/carer this can be a positive yet challenging time.

8.3.7 Under the Special Educational Needs provisions of the Children and Families Act, parent carers will have more choice and control about the support that they receive. The Act will extend the SEN system from birth to 25, giving children, young people and their parents greater control and choice in decisions and ensuring needs are properly met.

### **8.4 Carers from Black and Minority Ethnic groups**

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 associated with certain conditions, cultural barriers that hinder access to services or misconceptions about extended family support.<sup>4</sup>

In RBWM, 16.7% of the carer population are from BME groups. This ranges from 7% of the carer population in Bisham and Cookham to 29.9% of the carer population in Boyn Hill. The largest BME carer populations are in the Other White, Pakistani and Indian groups.

### **8.5 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. 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.<sup>56</sup>

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.

### **8.6 Distance caring**

Managing caring at a distance' refers to supporting/caring unpaid for an ill, frail or disabled relative, partner or friend who may be living in another part of

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<sup>4</sup> Half a Million Voices: Improving support for BAME Carers (Carers UK, 2011)

<sup>5</sup> <https://www.nhs.uk/CarersDirect/carerslives/aboutcaring/Pages/out-and-caring.aspx>

<sup>6</sup> [https://stonewall.org.uk/what\\_we\\_do/research\\_and\\_policy/health\\_and\\_healthcare/3480.asp](https://stonewall.org.uk/what_we_do/research_and_policy/health_and_healthcare/3480.asp)

## **Carers Strategy 2014-2017**

the town, region, country or the world. The role of a carer can be difficult if they live a long distance from the person they are caring for. With family members now more geographically dispersed there are many more people caring for a loved one at a distance. This can be challenging both in terms of organising the care and support that someone may need and having the confidence that their loved one is being taken care of. For the carer themselves this presents challenges in terms of not only looking after their own family but also their ability to remain in employment. Technology particular has role to play here and will need to be explored through the implementation of the strategy.

## **9. Impact of Caring**

### **9.1 Health and Well-Being**

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.

The 2013 Carers Week report 'Prepared to Care?' highlighted the negative impact of caring on carers health and well-being. 61% of carers have suffered from depression and 92% feel more stressed because of their caring role.<sup>7</sup>

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

### **9.2 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.<sup>8</sup>

Carers eligible for Carers Allowance – a financial benefit worth £59.25 per week – must care for 35 hours or more a week and earn less than £100 a week after tax. In August 2013 there were 720 carers claiming Carers Allowance in RBWM, equivalent to £2,237,040 annually. The number of claimants has increased in the last ten years (370 in 2003 to 720 in 2013), correlating with an increase in high intensity caring. However, it is estimated in RBWM that 377 carers are missing out on total of £1,171,100 Carers Allowance every year.<sup>9</sup>

### **9.3 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 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. 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 socially isolated.<sup>10</sup>

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<sup>7</sup> Prepared to Care? (Carers Week 2013)

<sup>8</sup> Caring and Family Finances inquiry (Carers UK, 2014)

<sup>9</sup> <http://www.carersuk.org/professionals/resources/research-library/item/3353-carersallowancetakeup>

<sup>10</sup> RBWM carers survey 2012

Social isolation can be particularly prevalent for young carers, who often miss out on opportunities to socialise with friends due to pressures of their caring role, or even face bullying for being 'different.' Young people may be afraid to ask for help, for fear of upsetting the family, or being taken in to 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 at all.

### **9.4 Participation in work, education and training**

More than half (2.8 million) of England's 5.3 million carers aged 16 or 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.<sup>11</sup>

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 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 11 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) and are likely to be a group with high support needs.

## **10. What have carers told us locally?**

10.1 This strategy has been developed with the involvement of carers, RBWM, health partners and the voluntary and community sector. Information and feedback has been collected through a number of sources including surveys (paper based and online), specific carer workshops, existing feedback and consultation reports as well as attendance at a number of established carer forums and partnership boards to ensure that the resulting information reflects the diverse needs of carers and their experiences.

10.2 Below is a summary of the key issues and concerns raised by carers, which have been consolidated under a number of themes. Some of the things that carers told us:

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<sup>11</sup> Prepared to Care? (Carers Week 2013)

## Information and Advice

- Access to information and advice was seen as the one of the top priorities for carers, and whilst it was recognised that there is information around it lacks co-ordination.

*“There is a lack of information, too many departments and organisations to navigate”*

- Information and advice needs to be concise, jargon free, in a variety of formats, up to date and in a variety of locations in the borough.

*“I would like information that is simple and quick to read”*

- Good information and explanations about social care in general is needed. Carers need an understanding of social care, assessments and entitlement. Processes and who to contact can be very confusing.

*“Finding out information can be difficult, particularly for carers who work and become a carer for the first time. There needs to be better information on entitlements, where to go for what, one point of contact so you are not passed around to different places.”*

- Information of different kinds will be needed by carers at different points/events in their lives e.g. diagnosis, crisis/emergencies, hospital discharge, returning to work.

*“It would be useful to map a carers pathway that looks at all the different ‘transition’ points that carers experience and what is needed at each e.g. from when you first become a carer to when your caring role comes to an end.”*

- There is a big demand for advice on benefits and money matters, particularly support to complete all the different forms.

*“There needs to be more financial advice and support.”*

## Carers Health and Well-being

- A significant number of carers felt that they weren't able to look after their own health and well-being as a consequence of their caring role. Being offered a health check and a flu jab was highlighted as a priority for carers.

*“Need Carers MOT health checks – these should be compulsory.”*

- The role of the GP was seen as essential in supporting carers' own health but it was felt that they lacked awareness of carers and the understanding of the carers role.

## Carers Strategy 2014-2017

*“Start with GPs – They don’t seem to understand what it means to be a carer. There is a lack of awareness – staff need more training on carers needs and how to support them.”*

- The Carers Time Out card was recognised as a really valuable benefit for carers.

### Breaks for carers

- Access to breaks were viewed as very important and whilst some carers were happy with the opportunities they’d had to have a break, others felt that more could be done to support carers.

*“I need regular, inexpensive and suitable respite”*

*“I only need very short respite i.e. someone to be with my husband while I went to see a film that I like.”*

*“In my particular situation I feel quite lonely, tired and often depressed because I don’t get any break from caring.”*

*“Carers need time to themselves but the cost of outside care is too high”*

- The availability of small carer grants was highlighted as something that would really make a difference.

*“Small grant awards make the carer feel valued and gives an opportunity to take a break.”*

- Carers highlighted the fact that they need to know that services/support will be readily available should an emergency occur and who to contact when they are needed.

*“We need contingency plans if something happens to the carer.”*

### Identification of carers and awareness of support available

- Carer awareness and identification of carers was seen to be lacking in RBWM. It was felt that many do not identify themselves as carers and therefore there are many ‘hidden’ carers. More needs to be done increase the identification of those who are caring.

*“Identification of carers is a gap and a challenge. People don’t identify themselves as carers and equally they are not identified by organisations/professionals. The language used is very important.”*

- GPs were viewed as essential in identifying carers but this was limited to being put on a register.

## Carers Strategy 2014-2017

- It was recognised that there is quite a lot of support out there for carers but it can be difficult to find.

*“Awareness of support available needs to be improved – I didn’t even know anything about a carers’ assessment.”*

*“We need a role like the Dementia Care Advisor, to help you navigate your way through the process.”*

### **Training, support and education**

- Access to training and education programmes were highlighted as ways of better supporting carers. In particular the need for practical training around moving and handling, back care and coping with challenging behaviour.

*“We need manual handling training for carers – the back care clinic used to be a great resource.”*

- The 6 week dementia course provided by the Older Persons Mental Health team was really valued by carers and they thought that something similar could be developed for other areas.
- Support for young adult carers was viewed as a gap in service provision, particularly advice and support on gaining employment.

*“For young adult carers there is an increased risk of experiencing mental health problems. The caring role also has an impact on their prospects of gaining employment.”*

### **Key messages from parent carers about their needs and their family’s needs**

Within RBWM there are a range of channels to seek the views of parents and carers on their individual packages of care and to engage them in the wider strategic planning of services for children with additional needs.

These include:

- Consultation with families as part of the assessment and review process of their child’s plan to ensure feedback is taken forward
- Regular evaluations of services and activities through the Short Break services
- Informal feedback is gathered from parent carers through various parent groups e.g. Parents Share Group and the Early Bird parental support
- Parent Carer RBWM enables parent carers to have a direct dialogue with the RBWM to influence and improve services for children with additional needs
- Formal consultation on the statutory Short Break statement

## Carers Strategy 2014-2017

- Annual family feedback form is used within the Children and Young People Disability Service to gauge families' views on the effectiveness of services provided and to identify gaps in provision and areas for development.
- Parents and Carers Consultation Group (electronic) to consult with parents on strategic pieces of work/projects such as the design of arrangements with support worker agencies.

The needs of parent carers will vary from family to family but some common themes emerge, parent carers have told us they value:

- The input of a single keyworker to co-ordinate their plan as there are often many different professionals involved in the care of their child or young person.
- Their child/young person accessing a short break in a safe environment whilst they have a break from their caring responsibilities and spend time with other siblings.
- Affordable, flexible short breaks provided for different ages and needs and across the 3 main localities in the borough with reliable and well trained staff able to meet their child's specific needs.
- Receiving regular information on short breaks services and how to access them.
- The choice, control and flexibility over services they receive through the Direct Payments scheme.
- Support programmes for parents such as the Early Bird course and other specialist early years groups to give them better knowledge and understanding of the child's needs and strategies to support them.
- Information sessions on common areas of concern for parents of children with additional needs e.g. DLA and other benefits, supporting children and young people's sleep, puberty and transitions to adulthood.
- The support provided by meeting with other parents in similar circumstances who dealing with the same challenges, sharing information and ideas and knowing they are not alone.

*Comments have included:*

- *I have found the keyworker time very helpful and felt listened to.*
- *Specialist Groups (Look and Listen) have been excellent both in terms of allowing X to play and learn but also to meet other parents with similar issues.*
- *Early Bird was very good to understand the strategies to deal with Autism. You get to voice your concerns and share your joys with other parents in a similar position.*
- *Parent information session on sleep... one of the most effective courses I have been on.*
- *I love the way you organise different activities we can try out at little cost and in a safe environment.*
- *Respite care has given me a break to get to the gym or go for a walk – invaluable.*

## Carers Strategy 2014-2017

- *(Short Breaks) I get to spend time with my older children knowing X is not missing out but having her own fun at the same time.*
- *Use of Direct Payments has worked well and given flexibility.*

### Key messages from Young Carers about their needs

Young Carers attending the local Young Carers Service were asked for their views via a short questionnaire. Albeit a small number, 22 young carers responded, their views and comments provide a helpful contribution and insight into present provision and need.

- 86% rated the Young Carers Service as good or excellent (64% as excellent)
- 86% rated the support in RBWM as good or excellent (50% excellent)
- 45% indicated there was an impact on their social Life/ going out
- 32% indicated that there was an impact on their education
- 32% indicated that there was an impact on their stress levels
- 23% indicated that there was an impact on their health

More open questions elicited a variety of responses summarised below.

Please tell us about the greatest effect caring for someone has on you:

- *I don't go out often*
- *The stress of having to watch out for mum and help my brother*
- *Proud and happy*
- *Caring for someone has made me more responsible*
- *Missing out on things*

Tell us about the support you receive?

- *One to one support and regular activities*
- *I get support from trips out, meeting others, family, young carers, Family Friends organisation*
- *School counsellor and friends*
- *Activities and stuff to help me care for my brother*
- *I receive support by meeting people in similar situations to myself, it has helped me to speak my mind*

What things could be done to make your life better?

- *Support for studying*
- *Some help because I get stressed*
- *For my mum to be better*
- *Maybe getting to know my brother better by going out with them separately*
- *More time with my parents*
- *Yes, keep up your (Young Carers Group) amazing work :)*

## **11. How are we supporting carers in the Borough now?**

RBWM and WAM CCG currently fund a number of specific carers' support services as well as respite or short break opportunities for the service user that also have the effect of supporting carers.

- Carers 'Time Out Card' offering free access to local leisure centres at off peak times.
- Carers training programme for people caring for someone with Dementia.
- Young Carers project.
- Funding to support the delivery of activities throughout national carers week.
- Information, advice and support service provided by Berkshire Carers Service.
- Carer support workers, including specific support to the black and minority ethnic community.
- Carers emergency card scheme.
- Grant funding to a range of voluntary sector organisations to provide support services to carers.
- Respite and short breaks.
- Day services in Windsor and Maidenhead.

Specific support for parent carers needs include:

- Short breaks - including Flying High Playscheme, 'Masters' Group of teenagers at Saturday Club and Buddy Group Youth Club for 12-18 year olds.
- A social group for young people aged 10-18 with physical disabilities and ensured more family activities are accessible for children and young people with physical disabilities.
- Under 5's singing and story time sessions at Saturday Club and ensured more family activities were open to children from 3 years up.
- Contracts with a range of Support Worker agencies to meet the varied needs of children and young people with additional needs.
- Work with mainstream leisure centres to provide specialist activities for children and young people.
- Life Skills Project for 16-25 year olds to support young people with the development of independent living skills.
- A range of Parent Information sessions in conjunction with Manor Green School based on topics suggested by parent carers.
- Directory of Short Breaks so parents know the range of activities on offer and how to access them.
- Breaks for carers in addition to their child's respite services with the option of Direct Payments for Social Care Services.
- Referral for counselling services to support their emotional wellbeing.

## Carers Strategy 2014-2017

Outlined below is the expenditure on carers services in 2013/14:

| <b>Service</b>  | <b>Expenditure<br/>£'000</b> |
|---|------------------------------|
| Short term care provided to in a residential home setting or as a short break to adults and children. | 2,094                        |
| Day Services  | 1,698                        |
| Carers week   | 3                            |
| Carer Education programme   | 10                           |
| Voluntary sector grants   | 392                          |
| Carers Emergency cards  | 10                           |
| Carers support workers  | 119                          |
| Young carers project  | 78                           |
| <b>TOTAL</b>  | <b>4,404</b>                 |

### **12. Other areas of work**

Alongside the work of the carers strategy there are a number of inter-linked strategies which contribute towards delivering the priorities and objectives outlined. These include:

- Dementia strategy and action plan
- End of Life strategy
- Autism strategy
- Prevention and Enablement strategy

**13. Delivery Plan**

This delivery plan will keep us on track throughout the implementation of the strategy and will allow us to evaluate progress. It is recognised that due to the changing legislative landscape in social care and health services that these actions will need to be kept under review as more information emerges from Central Government. In planning how support will be delivered to carers it will be necessary to review existing services and ensure that they are aligned to the priorities identified within this strategy and where gaps exist we will need to work with the market to develop new models of support and the services that carers need. Full baseline information is under development to ensure the impact of the strategy can be measured.

| <b>RBWM integrated Carers Commissioning strategy for 2014/15</b>   |  |  |             |                               |
|--|--|--|-------------|-------------------------------|
| <b>Key priorities for RBWM delivery plan – July 2014</b>   |  |  |             |                               |
| <b>Priority Outcome 1: Carers have access to good quality information, advice and support</b>  |  |  |             |                               |
| <b>Objective</b>   | <b>Actions</b>   | <b>How will we know we have been successful</b>  | <b>When</b> | <b>Lead</b>                   |
| Provision of co-ordinated and good quality information and advice for local carers via a number of channels.<br><br>Carers are able to access the services they need to support them in their caring role. | Audit of information requirements and understanding of key issues for carers. Resources targeted at hard to reach carers.<br><br>Carers support services, including partner agencies will ensure relevant advice and information is communicated in a range of different ways.<br><br>Carers information pack to be provided to all newly identified carers. | Increase of 10% carers accessing advice and information from the Carers Service in the voluntary sector.<br><br>Numbers using Carers service advice line.<br>Numbers using RBWM carer web link.<br><br>Carers information pack in place, designed by carers. | Autumn 2015 | RBWM/WAM CCG/Partner agencies |

Carers Strategy 2014-2017

|  |  |  |  |  |
|--|--|--|--|--|
|  | <p>Development of the local offer in children's service with specific sections on parent carers and young carers.</p> <p>Develop and maintain a directory of services and support in RBWM specifically for and/or which meet the needs of young carers. Involve Young carers in deciding which services and support need to be included.</p> <p>Explore opportunities for training for carers and identify best practice in carers training.</p> <p>Extend CBT training for dementia carers.</p> <p>More effective intelligence gathering on admission and discharge from acute services to inform support for carers. Develop and exit survey for carers in Hospital Discharge experience to inform the changes required.</p> | <p>Local offer meets the needs of parent and young carers.</p> <p>Young carer directory in place, which has been developed by young carers and receives positive feedback. Increase access and engagement with the Young Carers Project (200 carers over 3 years).</p> <p>Carers training programme in place for all carers to access. 30 carers accessing</p> <p>10% increase in number of carers attending CBT training.</p> <p>Increase in Identification of carers and support required for carers at the point of hospital discharge by 5%.</p> |  |  |
|--|--|--|--|--|

**Carers Strategy 2014-2017**

|   |   |  |             |              |
|---|---|--|-------------|--------------|
|   | <p>Undertake review of the range of support services currently in place for carers and alignment to identified priorities. Align commissioning intentions to funding arrangements of services for 2015/16.</p> <p>Ensure the range of services are in place for carers to meet the requirements of the Care Act.</p> <p>Peer support is developed to help carers help themselves.</p> | <p>Commissioned services are aligned to the priorities identified by carers.</p> <p>Support services in place support early intervention and prevention approach.</p> <p>3 new networks of peer support groups established.</p>  |             |              |
| <b>Priority outcome 2: Improve carers experience of navigating the services available</b>                                 |   |  |             |              |
| <b>Objective</b>  | <b>Action</b>   | <b>How will we know we have been successful</b>  | <b>When</b> | <b>Lead</b>  |
| Ensure that care pathways are co-designed and include appropriate references to carers and triggers to carers assessments | <p>Develop and launch a carer's pathway seeking feedback from carers to identify successes/need for change.</p> <p>Review current process for assessing carers and implement changes accordingly. Implement the new carer assessment statutory responsibilities for all</p>   | <p>Improved outcomes recorded for carers via the bi-annual carers survey. Carers are clear on where they can go for support.</p> <p>Increase in the numbers of carers assessments undertaken by 10%. Carers assessments are embedded in new adult and children's social care</p> | Spring 2015 | RBWM/WAM CCG |

**Carers Strategy 2014-2017**

|  |   |  |                    |                     |
|--|---|--|--------------------|---------------------|
|  | <p>carers.</p> <p>Adult and Children's services Task and Finish group established on transition of young carers to identify strength and weaknesses of current process.</p> <p>Establish a carers network across the voluntary sector to ensure that advice and support is co-ordinated.</p>  | <p>assessment arrangements.</p> <p>Transition protocol in place. Young carers experience a positive transition to adult services for themselves and their cared for.</p> <p>Carers network in place, with support co-ordinated through a single point of access.</p> |                    |                     |
| <b>Priority outcome 3: Support carers to access opportunities to take a break from caring</b>  |   |  |                    |                     |
| <b>Action</b>  | <b>Action</b>   | <b>How will we know we've been successful</b>  | <b>When</b>        | <b>Lead</b>         |
| <p>Ensure that a range of breaks are available for individuals to get a break from caring, both as a result of assessment of needs and also promoting universal opportunities available in the voluntary sector.</p> | <p>Maintain range and offer of short breaks to meet parent carer needs delivered through partner organisations.</p> <p>Review offer to ensure in line with needs of parent carers including age, location and range of services offered.</p> <p>Co-ordinate information on the range of break options available to carers through different</p> | <p>More Short break activities specifically for teenagers, under 5s, a social group for those with physical disabilities, more family activities and sessions for those in Ascot/Windsor.</p> <p>Information included as part of carers information pack.</p>        | <p>Spring 2015</p> | <p>RBWM/WAM CCG</p> |

**Carers Strategy 2014-2017**

|  |   |   |             |                                       |
|--|---|---|-------------|---------------------------------------|
|  | <p>organisations and identify gaps in provision.</p> <p>Increase investment in dementia short breaks for carers on their own and with partners to reflect targeted increase in dementia diagnosis rates (42% increasing to 67% in 204/15).</p> <p>Increase the use of carer personal budgets to provide flexible breaks and leisure opportunities for carers.</p> | <p>Increase of 10% of carers of people with dementia accessing short breaks.</p> <p>20 carers receiving a personal budget by end of 2015.</p>   |             |                                       |
| <b>Priority outcome 4: Increase carer identification</b> |   |   |             |                                       |
| <b>Objective</b>   | <b>Action</b>   | <b>How will we know we've been successful</b>   | <b>When</b> | <b>Lead</b>                           |
| Increase awareness of carers and their needs             | <p>Planned outreach and promotions to promote carer awareness and access information in targeted areas of the borough based on knowledge of the local carer population.</p> <p>Voluntary sector grants are aligned to increasing the identification of carers, particularly hidden carers, with appropriate performance</p>                                       | <p>Ensure that promotions such as Carers Week and Carers Rights Day reach out to 'hidden' carers. Other promotions are well planned and targeted to address unmet needs or hard to reach groups.</p> <p>Increase the numbers of carers registered on the Carers service database by 5% per annum.</p> | Summer 2015 | Carers partnership Board stakeholders |

Carers Strategy 2014-2017

|  |  |  |  |  |
|--|--|--|--|--|
|  | <p>measures in place to monitor progress.</p> <p>Implement a new Carer Aware e-learning course.</p> <p>More advice and guidance available for GP practices on the range of support available to carers.</p> <p>Engage GPs in carer concerns as part of Integrated Care Teams programme.</p> <p>Carry out awareness raising activities for key agencies to highlight how to identify young carers, for example INSET days in schools</p> <p>Target key services to highlight the needs and support available for young carers e.g. Schools, Early Help Services, Drug and Alcohol</p> | <p>All RBWM staff have undertaken e-learning programme. Increased awareness of carers agenda in all services.</p> <p>20% increase in the numbers of carers on GP carer register and subsequent referrals to relevant support service.</p> <p>Carers are recognised and their contribution, knowledge and perspectives are valued.</p> <p>Increased numbers of Young Carers identified (100% increase from 2014 baseline over 3 years – 2014-17).</p> <p>Increased engagement with known young carers in key service areas.</p> |  |  |
|--|--|--|--|--|

**Carers Strategy 2014-2017**

|  |  |   |             |             |
|--|--|---|-------------|-------------|
|  | services, Community Mental Health Team.  |   |             |             |
| <b>Priority outcome 5: Improve the health and well-being of carers</b> |  |   |             |             |
| <b>Objective</b>   | <b>Action</b>  | <b>How will we know we've been successful</b>           | <b>When</b> | <b>Lead</b> |
| Address the health needs of carers                                     | Target a % increase in all practices through Patient Participation Group network   | Increase of 10% of carers identified by GPs.            | Summer 2015 | WAM CCG     |
|  | Education and information programme for GPs on the health needs of carers. Implement Carer Ambassador scheme in GP surgeries | Increase of 10% of carers receiving a Health Check.     |             |             |
|  | Education, Health and Care Plan process to identify the needs of parents carers of children and young people.                | Improved quality of life reported in carers survey.     |             |             |
|  | Implement promotional events and activities that promote carers mental, emotional well-being and physical health.            | Findings from review implemented to improve flexibility |             |             |
|  | Undertake a review of the flexibility of access to health appointments   |   |             |             |

**Carers Strategy 2014-2017**

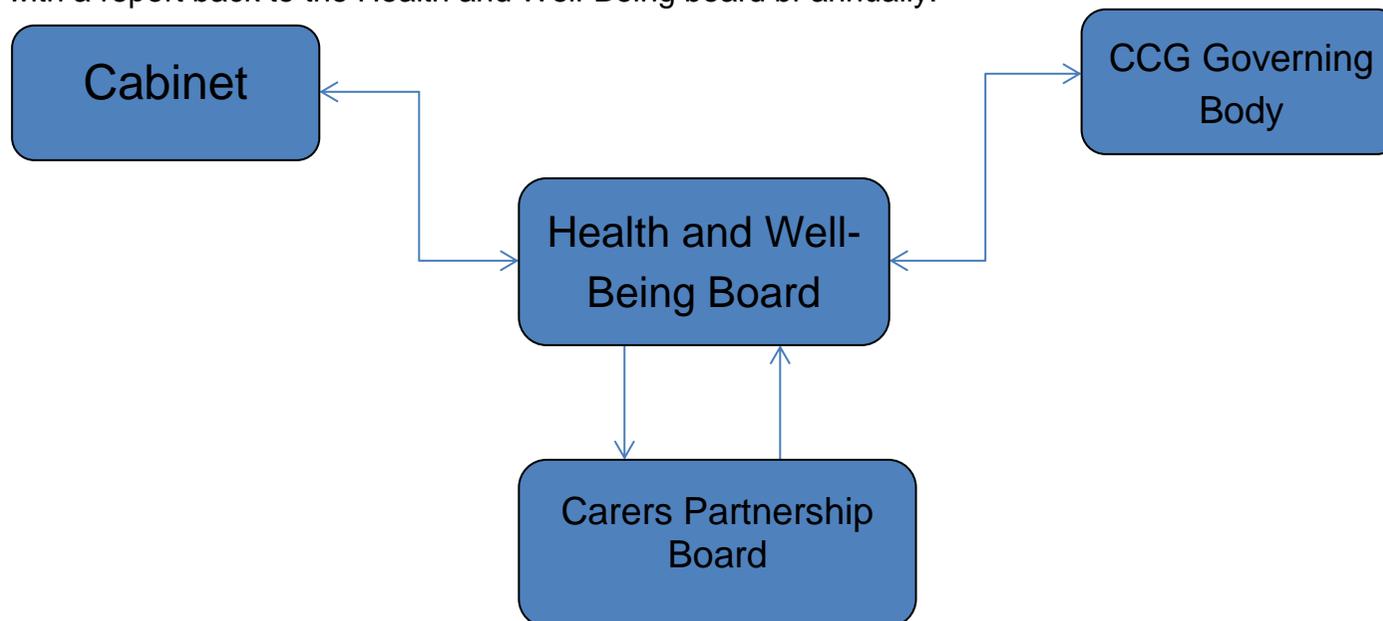
|  |  |  |             |                                       |
|--|--|--|-------------|---------------------------------------|
|  | for carers.  | of access to appointments for carers.  |             |                                       |
| <b>Priority outcome 6: Support carers fulfil their education, employment and life chances potential</b>                  |  |  |             |                                       |
| <b>Objective</b>   | <b>Action</b>  | <b>How will we know we've been successful</b>  | <b>When</b> | <b>Lead</b>                           |
| Assist carers to achieve their educational and employment goals through effective support                                | <p>Identify key services and support needs which need to be in place for all carers from the analysis of carers assessments and targeted work with working age carers.</p> <p>Support carers to access benefits advice and maximise their income.</p> <p>Support to be given to carers who are interested in sharing their skills through Care Bank or wish to take up volunteering opportunities.</p> | <p>Improved educational achievement/attendance</p> <p>Carers of working age are able to access to support to enter the workplace, remain in work or return to work.</p> <p>Increase in numbers (100) of carers claiming carers allowance, where they are eligible.</p> <p>Increase in the number of carers accessing volunteering opportunities.</p> | Spring 2015 | RBWM                                  |
| <b>Priority outcome 7: Ensure that carers support is targeted and reaches the diverse communities in the borough</b>     |  |  |             |                                       |
| <b>Objective</b>   | <b>Action</b>  | <b>How will we know we've been successful</b>  | <b>When</b> | <b>Lead</b>                           |
| To ensure the needs of harder to reach carers are addressed in the services and support that is commissioned for carers. | Hard to reach group of young families targeted via Health Visitors research - Army, traveller and Asian families in particular.  | <p>Increase in carer identification amongst harder to reach communities – 10%.</p> <p>Services commissioned are</p>  | Autumn 2015 | Carers partnership board stakeholders |

## Carers Strategy 2014-2017

|  |  |   |  |
|--|--|---|--|
|  | <p>Carry out review to ensure that current services and support to young carers are effectively engaging young carers from black minority ethnic groups and put in place promotion and engagement activities to tackle gaps/weaknesses identified.</p> | <p>meeting the needs of harder to reach communities – positive feedback received.</p> <p>Increased engagement with known young carers from black and minority ethnic groups through both the young carers project and other key services.</p> |  |
|--|--|---|--|

### 14. Monitoring progress

Implementation of the strategy and the associated delivery plan will be overseen by both the Health and Well-Being board and the Carers Partnership board. The carers partnership board will be responsible for reviewing progress against implementation on a quarterly basis, with a report back to the Health and Well-Being board bi-annually.



**15. Appendix**

Appendix 1- Carers UK – Working in partnership to deliver better outcomes for carers in the Royal Borough of Windsor and Maidenhead: Evidence report (April 2014)