

BUCKINGHAMSHIRE

A joint commissioning strategy for
Carers in Buckinghamshire

2010 - 2012

in partnership with

NHS
Buckinghamshire





Developed in partnership by:

Buckinghamshire Carer's Partnership Board
NHS Buckinghamshire
Buckinghamshire County Council

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Foreword

Every day, another six thousand people in the UK take on a caring responsibility. At any one time carers make up around 10 percent of the population.

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. Carers provide care equivalent in monetary value to that of funding the entire NHS. Carers give so much to society and the individuals they look after.

Caring can be a rewarding experience, yet as a consequence of their role carers experience ill health, poverty, reduced life chances and discrimination. People from all walks of life and backgrounds are carers - over three in five people in the UK will become carers at some time in their lives. Carers need support so that they can have a life of their own and so, where they want to, they can carry on with the task they have voluntarily taken on. In Buckinghamshire, support for carers can potentially reach ten percent of the population, around 45,000 people of all ages and in all localities and communities in the county. Of these 45,000 people around 15,000 will stop caring each year and another 15,000 will start a caring role.

Caring can and does affect us all; there are few people who don't know a carer even though they may not know that person is a carer. It is a major objective of this strategy to ensure that carers are known where they wish to be known, recognised for the valuable work they do and supported both to continue and to end their caring role. Nobody, especially young carers, should be forced into a role they are unable or unwilling to do.

Progress has been made to identify and support many carers in Buckinghamshire but we know that there are many other 'hidden' carers who continue to provide substantial levels of care with little or no recognition, with inadequate support and with poor information. Our aim is to ensure that all people in Buckinghamshire with significant caring responsibilities have:

- access to the information they require as carers
- access to the information they require outside their caring role
- knowledge of their rights as carers
- access to the level of support they need
- access to advocacy services

It is estimated that the value of support provided by carers in the UK amounts to £87 billion annually. Therefore, if only a small percentage were to give up caring, the economic impact would be very significant; this is as true of Buckinghamshire as of any other area of the country.

While it appears that most carers take on their caring role willingly, they can frequently feel unsupported and become vulnerable to physical and mental ill health as a direct result of their caring responsibilities.

It is important, therefore, that carers are adequately supported to be healthy and to be able to continue to provide care if they wish to do so.

I. Executive Summary

This is the first Buckinghamshire County Council, Carers Partnership Board and Buckinghamshire PCT joint commissioning strategy for carers. It has been developed following extensive consultation with local carers and the people who work with them and recognises that a joint commissioning strategy aimed at improving services for carers should also enhance the quality of life for the people they care for as well as increase the effectiveness and efficiency of health and social care services.

The partners in this strategy recognise the importance of supporting carers to maintain their own mental and physical health. Support in other areas of their life also an important role in allowing carers to continue with their caring responsibilities and help the people they care for maintain their independence.

In autumn 2007, BCC and the PCT signed an agreement to develop joint commissioning structures. The joint structures will be extended to include a joint post that will incorporate service-user engagement and carers.

A conservative estimate is that the economic value of the contribution made by the 45,000 plus Buckinghamshire carers is £5million a week. The Council acknowledges and appreciates the valuable role of carers in caring for those in need.

We know that carers need more help and support, not only in being a carer but also with having a life outside of their caring role. We will work closely with our partners to ensure the successful implementation of this strategy and are committed to ensuring that the service developments relating to carers are carer led.

There are three principal types of carer:

1. **Adult carers** - adults caring for adults over the age of 18, this includes parents caring for their adult children.
2. **Parent carers** - parents caring for a child or young person under the age of 18 who has a disability.
3. **Young carers** – children or young people under the age of 18 who are caring for either another child, young person or an adult

The strategy focuses mainly on adult carers and a separate strategy is being developed for Young Carers and Parent Carers. However, the importance of transition arrangements and the need to work together is recognised in the document.

The strategy outlines the vision for carers and the case for changing the way we work now. It shows the current position of Buckinghamshire both in terms of development over the period of the first strategy and in terms of comparison with other local authorities.

Linking in with the five outcomes of the 2008 National Strategy five “Big Ideas” have been developed with carers and stakeholder organisations, and these will form the basis for work with carers and commissioning strategies for carers in the coming years.

2. Introduction

What the strategy is about

This strategy is about commissioning services for carers, working with partners to achieve outcomes that will help and support carers regardless of their age, locality, community, or the needs of the people they look after.

It sets out the intentions of Buckinghamshire County Council (BCC) portfolios for Adults and Family Wellbeing (A&FW) and Children & Young People (C&YP); and NHS Buckinghamshire Primary Care Trust (BPCT), in supporting carers over the three years from 2010 to 2012.

What is a commissioning strategy?

A commissioning strategy is a formal statement of plans for securing, specifying and monitoring services to meet peoples' needs at a strategic level. It applies to services provided by the NHS and Local Authority, other public agencies and the private and voluntary sectors, but for the focus of this strategy it will include health and social care objectives.

This commissioning strategy is a plan which will:

- Effect change in the overall configuration of carer services to meet the needs of carers in Buckinghamshire.
- Ensure service change is commissioner led, based on evidence of what works best.
- Provide a statement of commitment about the way in which the commissioning agencies intend to purchase services for the population in the future

This commissioning strategy will be structured to provide an understanding and guidance around the following:

- The vision for BCC and BPCT for the commissioning and delivery of services to carers
- The context for the commissioning of services, including the key drivers and how services have developed.
- The values and principles in our approach towards commissioning of services.
- How services across health and social care have performed against commissioning priorities and service targets.
- Needs of carers in Buckinghamshire in relation to health and social care.

- The services available and where they are not available.
- The resources to fund the commissioning of services.
- What we need to do next – identifying commissioning priorities and the big ideas for action over 2009 to 2012

How the strategy builds on what has come before

This strategy replaces the previous strategy: **“A Strategy for Carers in Buckinghamshire, a Five year Multi-agency Strategy 2006-2010”**

The previous strategy was developed from a best value review of services for carers that was commissioned after the publication of the first National Carers’ Strategy in 1999. It helped to deliver fundamental changes in the delivery of services for carers in Buckinghamshire starting with new governance arrangements for carers:

- The formation of a Carers’ Policy Strategy Group which was chaired by a Carers’ Champion, a member of the County Council Cabinet. The group consisted of representatives from the voluntary and statutory sectors and was responsible for overseeing the delivery of the Improvement Plan.
- The appointment of a Carers Services Manager to coordinate the response to the Best Value Review and to complete the Improvement Plan.
- The setting up of an in-house Carers Group consisting of operational and support staff within BCC and the Oxfordshire & Buckinghamshire Mental Health NHS Foundation Trust (OBMHT), to carry out the practical tasks involved and engaging other staff as required.

These initiatives resulted in the following:

- The commissioning of a single carers’ centre and the development of a comprehensive network of information, advice and support, including advocacy, for carers in Buckinghamshire.
- The commissioning of new projects involving the private, voluntary and statutory sectors.
- Pilot projects to test ideas of how best to support carers.
- Improved delivery of respite breaks through BCC operational teams.
- Improved delivery of respite breaks through joint funding arrangements with the Mental Health Trust
- A new carer’s assessment form; a training programme in carer awareness; and the need for assessment delivered to all care management and social work staff in BCC.

- A protocol with Children's Services on assessment of 16 and 17 year old carers

This strategy will build on the progress made since the publication of the first strategy by including updated commissioning priorities, and in reflecting the drivers and priorities as set out in the new National Carers Strategy (2008). The funding for carers services, previously known as the Carers' Grant, will now be part of the area-based grant that funds the Local Area Agreement (LAA).

Scope of the strategy

This strategy covers all carers in Buckinghamshire regardless of their age, their location in the county, or the location, illness, disability, age or gender of the person or persons they are looking after. Carers who live outside Buckinghamshire but who care for a person or persons within the county will be referred to their local carers' centre or social services department.

The scope includes carers of those who use services commissioned from health and social care (adults and children) and those unknown to either health or social care but who are identified by partner agencies.

Partners in the strategy represented on the Carers' Partnership Board are currently carers in Buckinghamshire working with the following voluntary and statutory organisations:

- Buckinghamshire County Council
- NHS Buckinghamshire Primary Care Trust
- Oxfordshire & Buckinghamshire Mental Health NHS Foundation Trust
- Aylesbury Vale District Council
- Buckinghamshire Hospitals Trust
- Carers Bucks
- The Alzheimer's Society
- Crossroads (Caring for Carers)

There will be a joint commitment with the PCT to build on the partnership working for carers carried out over the last five years in the carers' centre, initially funded by the Partnership Development Fund, by the County Council through the Carers Grant, and then by carers funding within the Area-Based Grant.

The strategy is intended to be a reference document in setting out a broad direction of travel and key priorities for the development and delivery of services for carers that will require translation into specific priorities and actions within other A&FW and PCT commissioning strategies responsible for different care groups.

For example, it will state the broad priorities in commissioning services for young carers and parent carers of disabled children whereas the detailed commissioning actions will be contained in a separate C&YP commissioning strategy.

Definition of “carer”

Who is a Carer?

There is no nationally accepted definition of “carer”. The government has made it part of the new National Strategy to find a widely accepted definition, for now they admit the failure of central government to provide a lead:

“Across government, the term ‘carer’ has different meanings in different pieces of legislation. A carer spends a significant proportion of their life providing unpaid support to family or friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.”

Buckinghamshire has adopted this definition:

A “Carer” is someone of any age who, without payment, looks after or provides regular and substantial help to family members, neighbours or friends who are sick or disabled, vulnerable or frail. This includes parents of children with disabilities and young people who may themselves be helping to care for a family member.

The role of “Carer” should not be confused with “care worker” or “care staff” who are either undertaking a caring role as part of paid employment or as volunteers attached to a voluntary organisation. This distinction is made in law through the Carers (Recognition and Services) Act 1995, which says that ‘a carer’ is someone who provides or intends to provide a substantial amount of care to someone else on a regular basis and that they are not employed to provide the care.

In Buckinghamshire, ‘substantial’ is defined as meaning that if the carer chose to stop providing the support and care to the person, then that person would be at significant risk and may not be able to continue to live independently in the community.

“Informal Carer” is sometimes used interchangeably with the word “Carer” as is “Family Carer”. Both these terms have their detractors and their champions so the word “Carer” will be used throughout this document.

There are three broad categories of Carer:

Adult Carer

an adult caring for another adult such as a spouse, partner, friend or relative.

Parent Carer

an adult who cares for a child with a long-term illness or disability.

Young Carer

a child or young person who is carrying out significant caring tasks for a sick or disabled relative or friend and assuming a level of responsibility for another person which would usually be undertaken by an adult. According to Carers UK there are about 50,000 Young Carers in the UK.

The difficulties facing carers can vary widely. Spouse carers are likely to be older and in poorer health, whereas carers of parents are usually of working age and often have dependent children.

People who are caring from a minority, ethnic background may have additional needs including difficulties in accessing services due to cultural and language barriers.

Young carers carry burdens that people of their age should not have to bear and have blocks to achievement placed in their way at a crucial age.

Carers of people who have a suddenly acquired disability, through an accident or stroke for example, have been found to be prone to post-traumatic stress disorder.

Governance on how the strategy will be delivered

Recently revised governance arrangements are now in place with better direct carer representation via a new Carers' Partnership Board (CPB).

The terms of reference for the Partnership Board are:

- To champion the needs of all Carers in Buckinghamshire and ensure that services, information, advice, health advice and advocacy are locally both accessible and responsive.
- To ensure that services for Carers are effectively planned, delivered and reviewed.
- To ensure that best use is made of available resources.
- To oversee and manage the implementation of the Multi-Agency Strategy for Carers in Buckinghamshire, to review it and monitor the implementation of the associated action plan.
- To ensure that there are effective protocols and joint working arrangements in place with other services.

- To ensure that Carers are aware of Buckinghamshire's Safeguarding Policies and Processes, and to their right to protection from abuse.
- Through partnership working, to set the strategic direction for services for Carers in Buckinghamshire in response to need, and local and national policy

The CPB will have responsibility for monitoring the development and progress of this strategy and advise on new priorities where required. It will provide recommendations for key decisions within A&FW and the PCT's decision-making bodies concerning the carers' spending plan and service development or reconfiguration proposals.

3. The Vision for Carers

The National Vision

The government has set out their vision in the new National Strategy (Carers at the heart of 21st century families and communities - “A caring system on your side. A life of your own.” Department of Health 2008) as follows:

“Our vision is that by 2018, 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, while enabling the person they support to be a full and equal citizen.

By 2018:

- 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 as full a life as possible outside 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, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

The Local Vision

The local vision for carers, as agreed for the first strategy and reaffirmed with new additions by the Carers Partnership Board on December 1st 2008 is:

- Carers will have access to health, financial and all other relevant information that will help them in their caring role and enable them to have a life outside caring
- Carers will be recognised as full and equal citizens in their own right
- All Carers in Buckinghamshire will have equal access to the services provided for them regardless of their economic status, employment status, ethnic origin, the category or economic status of the person they care for, age, gender and the locality or area of the county they live in

- Carers in Buckinghamshire will be recognised as partners in the care of the people they look after, this will be reinforced by the continuation of the relaxation of charging for carers' services
- Carers will be supported to look after the person they care for
- Young Carers will be protected against providing levels and types of care inappropriate to their age and gender. Young Carers who are unable or unwilling to reduce their caring role will be helped to lead a full and active life outside caring and to maximize their educational and leisure opportunities in line with other young people of their own age.

The six elements of this vision have been translated into five “Big Ideas” and an action plan developed to carry out the activity necessary to make the vision a reality. The vision is also broadly in line with the “Five Outcomes” outlined in the National Strategy for Carers.

How will the vision be delivered?

The Carers' Partnership Board will be responsible for ensuring that the strategy delivers against the vision for carers' services. The Service Development Manager (Carers) will be responsible for the implementation of the strategy, initiating and leading on projects in delivering the actions required, and reporting on implementation progress to the board.

4. The Case for Change

In Buckinghamshire we will ensure that the provision of services for carers and the way we commission them supports locally the implementation of national policy.

Making it happen - the centrality of commissioning to drive improvement

Commissioning is now formally seen as the vehicle for delivering improvement and change across the NHS and social care. For the first time commissioning capability and competency is now formally being assessed within the performance regimes of the both the council and the PCT.

National Drivers for Change

(Further legislation is referred to within the Appendix)

National Service Framework for Older People.

As people become older and more disabled there is often increased dependency on one or more family members or friends. In recognition of this carers are included in the assessment of dignity and care standard. Health commissioners include carers in service development and service re-design through consultation and carers are involved in the training of doctors and student nurses.

Local Authority Circular {(DH) (2009) 1}

The Local Authority Circular states that “councils are expected to have started to develop commissioning strategies which include “a market development and stimulation strategy” to ensure that commissioning decisions increase rather than decrease the range of provision on offer, including for self-funders.

Caring with Confidence Programme

The “Caring with Confidence” programme is part of the Government’s renewed attempt to involve family members and other carers as care partners, with appropriate training to enable carers to develop their skills and confidence. Local authorities can bid for money to fund these training courses as Buckinghamshire has done and has been successful in its bid.

The King’s Fund Standards

Buckinghamshire County Council, since the previous strategy was signed off, has measured itself against the five King’s Fund Standards of a good service for carers.

These are:

1. Services providing information which is comprehensive, accurate and appropriate, accessible and responsive to individual needs.
2. Services offering a break, working in partnership with the carer and the person being supported, that are flexible, give confidence and can be trusted.
3. Services offering emotional support, either on a one-to-one basis or in a group, that are sensitive to individual needs, offer continuity and are accessible to all carers.
4. Services supporting carers to care and to maintain their own health and wellbeing by offering training, health promotion and personal development opportunities that are responsive to individual needs.
5. Services which support carers to have a voice as an individual and/or collectively, are accessible to all carers and effective in bringing about change.

**The new National Carers' Strategy:
Carers at the heart of 21st century families and communities
“A caring system on your side. A life of your own.”**

The strategy sets out the following key commitments to deliver:

- Improving information and advice provision
- Training carers to be expert partners in care
- Training the workforce to provide better services and support for carers.
- Utilising the Third Sector more effectively to support carers
- Using Information about carers for better commissioning and planning of carer services
- Improving access to carer services
- Applying the Personalisation agenda to Carers
- Reviewing the structure of benefits for carers
- Expanding NHS services for carers
- Supporting Young Carers better
- Improved utilisation of the Annual Carers Grant
- Increasing breaks for carers.

The NHS Plan (Department of Health 2000)

Core principle 3 states that: The NHS will shape its services around the needs and preferences of individual patients, their families and their carers. The plan goes on to weave the needs of carers into the fabric of the plan in terms of consultation, action and respite service provision.

“Modernising Social Services” (Department of Health, 1998 White Paper)

The White Paper sets a national objective to enable carers to continue to care for as long as they and the service user wish; notes the diversity of carer needs; and requires local authorities to work with carers to identify these and offer genuine opportunities for shaping services.

The Carers (Recognition and Services) Act 1995

The Act came into force in April 1996. Where a local authority is carrying out an assessment of the needs of the user AND a carer provides or intends to provide a substantial amount of care on a regular basis, the carer may request that the local authority assesses his/her ability to provide (and continue to provide) care. The local authority must take the results of that assessment into account in deciding about service provision to the user.

The Carers and Disabled Children Act 2000

The Act, which came into force in April 2001, gives further reinforcement to carers' rights, including the direct provision of services to the carer as a result of an assessment, extension of direct payments to carers, and inclusion of a carer's assessment within a child's need assessment.

The Carers (Equal Opportunities) Act 2004

The Act came into force in April 2005. It places a duty on local authorities, in certain circumstances, to inform carers that they may be entitled to a carer's assessment. It also places a duty on local authorities, when they are carrying out a carer's assessment, to consider whether the carer works or wishes to work, is undertaking or wishes to undertake, any education, training or leisure activities. It also gives local authorities formal powers to enlist the help of health, housing and education authorities in providing support for Carers.

Valuing People March 2001, the national strategy for Learning Disability

The strategy stresses the need for reliable support services for carers of people with learning disabilities so that people with learning disabilities are enabled to achieve independence, choice and inclusion

National Service Frameworks (NSF)

National Service Frameworks (NSF's) are long term strategies for improving specific areas of care, setting national standards, identifying key interventions and put in place agreed time scales for implementation. Targetted at mental health, older people, long term conditions, all include reference to the need for improved support to carers. Within the NSF for older people, PCTs are required to involve older people and their carers in the re-design and commissioning of services.

Every Child Matters – Change for Children

This is a major national programme of change across children's services designed to improve outcomes for all children including being healthy, staying safe, enjoying and achieving, making a positive contribution and achieving economic wellbeing.

No Secrets: Guidance on developing and implementing multi-agency policies and procedures to safeguard vulnerable adults.

This guidance encourages partnership in the protection of vulnerable adults. It must be remembered that carers may be driven to harm those they look after and may also be harmed by the person they care for.

NHS Operating Framework 2009/10

The Operating Framework sets out an overview of the priorities for the NHS for the year. One key priority is that PCTs should work with their local authority partners and publish joint plans on how their combined funding will support breaks for carers, including short breaks, in a personalised way.

It also reinforces the need to support carers of people with dementia. This is particularly relevant to Buckinghamshire where the annual survey of carers shows a linked increase in ageing carers, ageing people being cared for and a concurrent increase in cared-for with dementia. This is the biggest burden being put on some of those least able to cope.

The Council's Prevention Strategy

A forthcoming prevention strategy will outline low-level intervention that can support carers in recognition of their role as one of the major factors in preventing admission to care or consumption of care services.

Local Authority Circular {(DH) (2009) 1}

The Local Authority Circular states that "universal, joined-up information and advice (is) available for all individuals and carers, including those who self-assess and fund"

Local drivers for change

Self Directed Support and Personal Budgets

The Adults & Family Wellbeing portfolio in Buckinghamshire has signed up to an ambitious programme of change to support the transformation of social care. The national strategy states that all councils in England must now implement personalised budgets in order to give people greater control of their social care.

The current system of social care is based upon local authorities matching a limited range of services to people's assessed needs. Demographic pressures are leading to spiralling costs, particularly in placements, and there is a widespread belief that there needs to be a fundamental rethink of how we provide social care services, required to

address the increased pressures on budgets as a result of demography, and increased expectations on the services by people who use it.

Two recent documents from the Department of Health (DH) set out the central role the government sees that personalisation and personalised budgets will play in the future delivery of social care services. In December 2007, 'Putting People First' set out a shared vision and commitment to the transformation of social care. This includes a vision which sets out that:

'Over time, people who use social care services and their families will increasingly shape and commission their own services. Personal budgets will ensure that people receiving public funded services use available resources to choose their own support - a right previously only available to self funders. The role of social care will change in this model with a much greater focus on enablement, advice and information giving'.

In January 2008, 'Transforming Social Care' provided further details on the significant resources that are being made available to support the transformation agenda and the delivery of personal budgets is stated to be an essential part of the overall agenda. In Buckinghamshire this resource will be deployed to manage the transformation agenda and a significant proportion of this allocated to support the move to individualised budgets. This agenda will underpin all of the commissioning priorities that relate to social care within this document.

The Local Area Agreement for Buckinghamshire sets out the priorities for the county for three years as agreed between central government and the local area led by Buckinghamshire County Council (BCC) with the Bucks Strategic Partnership, (BSP) and other key partners. The lead agency is Carers Bucks who have undertaken the target to increase carers on their database to a prescribed level.

because Every Adult Matters (bEAM)

'because Every Adult Matters' (bEAM) is the framework for Adult Social Care's response to the White Paper "Our Health, Our Care, Our Say." Alongside the statutory services to those most in need, Adult Social Care will seek to engage with a wider range of adults in order to:

- Provide better prevention and early intervention to promote public health and wellbeing
- Give people more choice and a louder voice
- Tackle inequalities
- Provide better support for people with long-term conditions.

'because Every Adult Matters' adheres to the principles enshrined in the "Dignity in Care" agenda, launched in November 2006, which outlines national expectations for older people's services that respect and promote dignity.

'because Every Adult Matters' further enhances and supports the Getting Closer to Communities (GC2C) scheme in Adult Social Care, by linking in with the various GC2C initiatives for increasing and improving community engagement and brings together four specialist services aimed at:

- vulnerable adults who would benefit from enhanced service for existing clients who might otherwise find it difficult to continue to maintain their independence
- non service-users who would fall outside our eligibility criteria of substantial or critical, but may need our services in the foreseeable future and who would benefit from getting clear advice on the wider services available within their local community.

The County Council Corporate Plan 2005 – 2009

Aim 5 of the Buckinghamshire Corporate Plan is: Provide support to help families cope with their responsibilities:

Aim 5 (b) in the Corporate Plan is to: "Increase support for carers and families including opportunities for respite care"

Buckinghamshire Primary Care Trust Operational Plan 2008

The operational plan includes reference to the need for services for carers and it proposes a target set around the proportion of carers receiving a 'carer's break'. This is still under consideration.

Buckinghamshire Primary Trust Strategic Commissioning Plan 2007

Emphasis is given to the need to promote self care for users and carers. Such investment can be cost saving and help to improve health and quality of life for those concerned.

5. Performance

This section looks at performance in two parts, one against key policy initiatives and the other against national performance indicators as set by central government.

5.1 Buckinghamshire performance against key government guidance and initiatives since 1999:

1999 The first National Carers' Strategy and the Carers' Grant:

In response to the new National Strategy, launched in 1999, an interagency Carers Strategy was developed between Milton Keynes Council, Buckinghamshire County Council, Buckinghamshire Health Authority and the three Carers Centres in Buckinghamshire and Milton Keynes.

Funding was agreed to commission several pilot projects which were funded by the Carers Grant. Achievements under the interagency Carers' Strategy included the improvement of carers' support through two carers' centres, allocating money to specific projects within them.

2001 – The Best Value Review of Services for Carers

Buckinghamshire held a best value review of services for carers in 2001. The review led to the setting up of new governance arrangements for carers' services, better use of the Carers' Grant and an Improvement Plan in 2002. The improvement plan addressed the failings in the usage of the Carers' Grant.

Newly simplified arrangements for spending grant monies by care management teams were introduced and funding was released for spending within the voluntary sector and the Buckinghamshire Mental Health Trust. The latter were allocated funds for use by a dedicated assessment team for carers.

The best value review identified 39 steps within its improvement plan for improving services for carers. As a result both Health and Social Care funded a variety of projects for Carers and developed further improvement plans for subsequent years between 2002 and 2005. Some of the projects were funded by the Partnership Development Fund which was intended to encourage joint working between the PCTs (there were then more than one) in Buckinghamshire and the County Council. As this funding ran out, and the PCTs felt unable to provide funding from their mainstream budgets, ongoing projects were funded out of the Carers' Grant.

2004 –The Carers (Equal Opportunities) Act

This new piece of legislation confirmed a shift in policy emphasis away from carers as adjuncts to the person they cared for to the carer in his or her own right. The Act gave carers the right to have their education, leisure, training and employment considered as a central part of the carer's assessment.

The Buckinghamshire response was to revise the carer's assessment, incorporate the terms of the Act, re-emphasise the rights given in previous legislation, including the right to a direct payment, and re-train all care management staff in the use of the new assessment form and its place in the process of assessing service users.

Carers had, for the first time in the County, the right to be recorded on the client index system (SWIFT) in their own right. This was completed by the end of 2005.

2005 – A Strategy for Carers in Buckinghamshire, a Five Year Multi-Agency Strategy 2005 to 2010

This Strategy was a direct descendant of the 2002 Best Value Review of Support for Carers and subsequent Improvement Plan. The Strategy's objective was to set out key priorities and actions for carer services over the next five years. It was governed by the multi-agency Carers Policy Strategy Group chaired by the Carers' Champion for Buckinghamshire County Council.

Key achievements include the maintenance of support for carers through continued allocation of carers' funding after ring-fencing was removed by government, and continued exemption from charging thereby supporting carers to access services without financial assessment.

2007 – The New Deal for Carers

This initiative introduced some dedicated funding for local authorities to commission a service to provide emergency care for carers should they become indisposed. The Buckinghamshire response was to draw up temporary guidelines for using the money immediately through care management and to integrate the need for a full scheme into the tender for a new carers' services contract. This has developed into the ICE (In Case of Emergency) scheme for carers run by Carers Bucks. Currently almost 200 carers are supported under the scheme.

2008 – The new National Carers' Strategy Carers at the heart of 21st century families and communities: "A caring system on your side. A life of your own."

This is an updated strategy which builds and expands upon the 1999 national strategy. It consolidates a shift in policy towards looking after the carer for his or her own sake.

The Buckinghamshire response has been to update its local strategy, as represented in this document, setting out updated key priorities and actions for the next three years.

5.2 Buckinghamshire Performance against Key National Indicators

The Council's performance for services to carers is measured and counted as part of its overall performance assessment within its annual Self Assessment Survey to the government.

It is measured in two parts:

1. The Performance Indicator NII 35
2. The numbers of breaks for carers that are delivered and recorded in the annual Self assessment Survey

1. The Performance Indicator NI 135

This is the National Performance Indicator for Carers which counts towards the Council's overall performance as measured annually by the Government. The definition for the indicator has gone through some changes. Initially the indicator counted the number of carers assessed or reviewed against the number of service users known to the Council. It was changed for 2005/2006 to an outcome based measure which counts the provision of a service as a single outcome arising from the carer assessment and as a percentage of the number of service users known to the council.

From 2008, the provision of service included "Advice and Information" which could be counted against the performance indicator

The table below sets out BCC's performance in increasing the actual numbers of assessments completed year on year.

Year	02/03	03/04	04/05	05/06	06/07	07/09	08/09
No. of Assessments completed	108	437	639	1082	1350	1556	1716
Increase on previous year		304%	23%	69%*	25%	15%	10%

*a new assessment form was introduced in 2005

The following table sets out BCC's performance against the new indicator (Provision of service as an outcome of an assessment and as a percentage of service users known to the council) between 2005 and 2008.

Year	Buckinghamshire %	England %
05/06	9.0	8.7
06/07	12.7	11.7
07/08	13.1	13.6

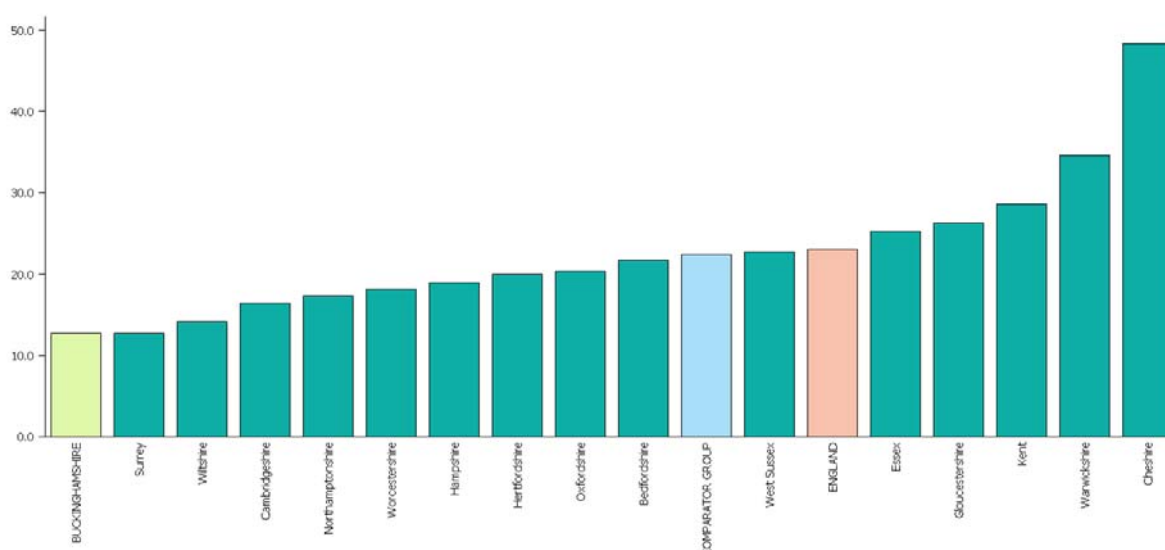
(Figures of carers in receipt of a specific carer's service, following assessment, as a percentage of service users in receipt of a community based service).

The council's performance against the outcome based measure, has improved steadily in Buckinghamshire and is slightly above the average for local authorities in England.

The next table shows Buckinghamshire's performance in comparison with other local authorities over a five year period and it has been approximately in the middle to the top third ranking until 2009.

Year	Outturn	Ranking
2004/05	5.6	89 (out of 150)
2005/06	8.7	74 (out of 150)
2006/07	12.7	43 (out of 150)
2007/08	11.9	86 (out of 150)
2008/09	12.7	91 (out of 97)

The outturn in 2008/09 increased numbers. However, a change in the indicator definition combined with the significant growth in the number of ‘in-Touch’ clients artificially drove down Buckinghamshire’s relative performance compared to other authorities.



Source: NHS information service: NACSIS RAP report 2009.

Although the Care Quality Commission recognised the improvement in numbers, saying: “Good performance typified by a higher rate” it shows the council has not significantly improved its performance against the indicator and that its ranking has dropped. Two key reasons are (1) a change in definition meant carers whose assessments resulted in Information and Advice only were included in the indicator for the first time.

Buckinghamshire had a significantly smaller proportion of its carers assessments resulting in Information and Advice compared to other authorities and therefore did not improve as much as other authorities; and (2) a recent initiative in providing low level preventative services to potential service users across Adult Social Care has resulted in a large increase in the number of service users known to the council, thereby having an impact on its measurement against the performance indicator.

2. The number of carer breaks

The number of breaks provided by the council in partnership with other organisations funded from the Carers Grant has steadily increased between 2003 and 2008 as seen in the following table.

Year	03/04	04/05	05/06	06/07	07/08
No. of Breaks	3,125	3,526	4,096	13,051	17,453

Buckinghamshire is performing well in respect of providing breaks. CSCI (now the Care Quality Commission - CQC) in 2008 reported that: "The numbers of carers receiving breaks services over the year came to a total of around 3,100 per council".

The definition of a break was wide and left scope for big variations between local authorities depending on the type of break offered. The emphasis on reporting numbers of breaks is now shifting and CQC is looking at what frameworks are in place to help carers and what outcomes they are producing.

6. Understanding Local Needs

What is known nationally?

It is estimated by Carers UK that there are about six million carers at any one time in the UK providing around £87 billion worth of care to those they look after. Of the six million, two million “drop out” each year but are replaced by another two million. Every day, another six thousand people take on a caring responsibility. Women are more likely to be carers than men - 42 percent of carers are men and 58 percent are women. A large and growing proportion of carers are over 60 years of age. Three-fifths of carers are looking after someone with a disability. 855,000 carers provide care for more than 50 hours per week and two thirds of working-age carers are in paid employment – this can mean that some carers effectively have two full time jobs. (Carers UK – all information on www.carersuk.org)

Carers tend to be regular users of health services as a result of their caring role. Two main reasons for referral to health services are physical injuries, such as a strained back, and stress-related illness. It has been estimated that carers are twice as likely as non-carers to have a mental health problem.

The Princess Royal Trust recently estimated that there could be up to 175,000 young carers nationally with 13,000 caring for 50 hours or more. Many of these children receive no support from statutory or voluntary services. Some young carers or their parents may fear that, if they draw attention to their situation, they will be taken into care. Children in families where a parent suffers from mental illness can themselves be at risk of developing mental health problems. In families where alcohol or drug abuse is a problem, children can be faced with a caring role which can create great anxiety. (PRTC information on www.carers.org)

Known needs of carers are:

- good information
- support
- recognition
- breaks from caring

Training for carers on proper handling and moving of their cared for in a safe and effective way, including the use of equipment, is another need, which could help to prevent many of the physical injuries carers can suffer.

Social support and assistance from their family and friends play an important role in maintaining the mental well-being of carers. Emotional support may mean having someone to listen to their problems, or help and advice from someone else who is, or who has been, a carer. GPs can help by identifying those who are carers, and by providing support and advice.

The government consulted widely before drawing up the latest National Strategy of Carers and the main messages coming through were:

- Carers needing more knowledge, guidance, information
- Variability in service provision and access for carers country wide
- Need for greater recognition of carers' roles and improved attitudes towards carers
- Lack of opportunities for carers
- Adverse financial impacts of caring
- Physical and emotional impact of caring

What is known locally?

The Joint Strategic Needs Assessment (JSNA)

The Joint Strategic Needs Assessment (JSNA) is the means by which Buckinghamshire County Council and Buckinghamshire Primary Care Trust will find out about and describe the current and future health, care and well-being needs of the people of Buckinghamshire. It will be used to inform the way in which services are organised and delivered in Buckinghamshire to meet the needs of the people. Carers are an integral part of the assessment.

Central to this is “Using carers' views to shape services and to define what outcomes people want from their services”. This aim is made more achievable in Buckinghamshire by the review of governance arrangements and the formation of the Carers Partnership Board.

The JSNA points out that “Carers have two main health problems: physical injuries such as a strained back; and stress-related illness” which reinforces the need for a multi-agency “Spend to Save” approach to supporting carers.

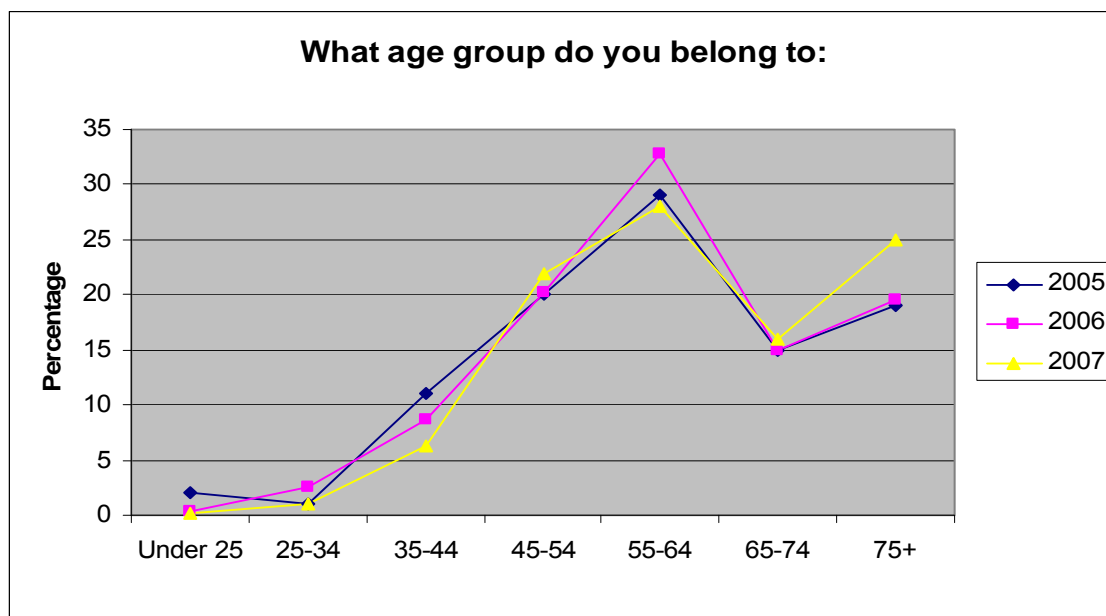
The future growth of the adult population in Buckinghamshire engaged in caring, and the hours per week they are likely to spend on their caring tasks is predicted in the following table:

Year	Population of Bucks	No of Carers	1 0-19 hours of caring	20-49 hours of caring	50+ hours of caring
2009	492900	45,090	34,897	3,721	6,472
2012	500400	45,776	35,428	3,778	6,570
2015	508600	46,527	36,009	3,840	6,678

The data in the table is taken from the 2001 Census data and calculated on the predicted population growth for the County until 2015.

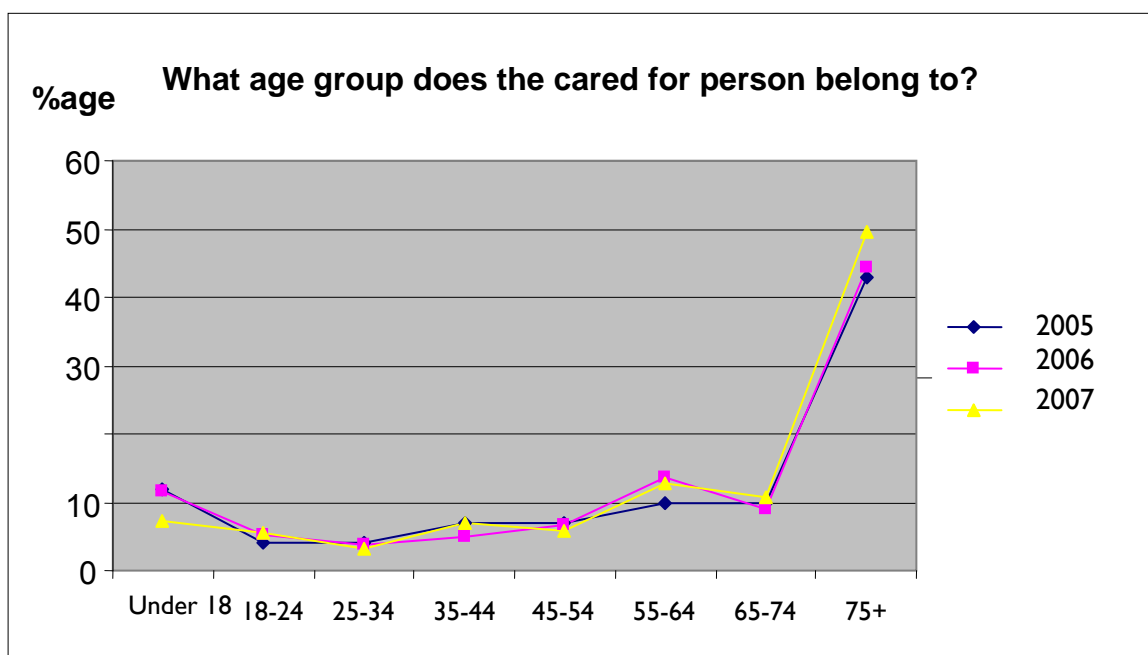
Some of the messages identified nationally have also been echoed by local consultation. Carers Bucks carry out annual surveys of both adult and young carers on behalf of the County Council. These surveys have provided important information about Carers in Buckinghamshire. It needs to be noted that a key role of Carers Bucks is to target those Carers in most need, i.e. those providing 50 plus hours per week, and therefore it will be this group who will constitute the largest amount of responses to the carer survey.

The following graphs and analysis draw upon key findings from the carer surveys between 2005 and 2008:



The table shows that the largest number of carers is within the 55 – 64 age group. There is however a rise in the number of carers in the over 75 year old group. The rate of increase in the older group of carers has accelerated according to the latest survey (2008) with 52 percent of carers now over 65:

2008 carers' survey (M. Hargreaves)		2008
Age of carer	Under 35	2%
	35-44	8%
	45-54	17%
	55-64	22%
	65-74	26%
	75+	26%
	No. of responses	857

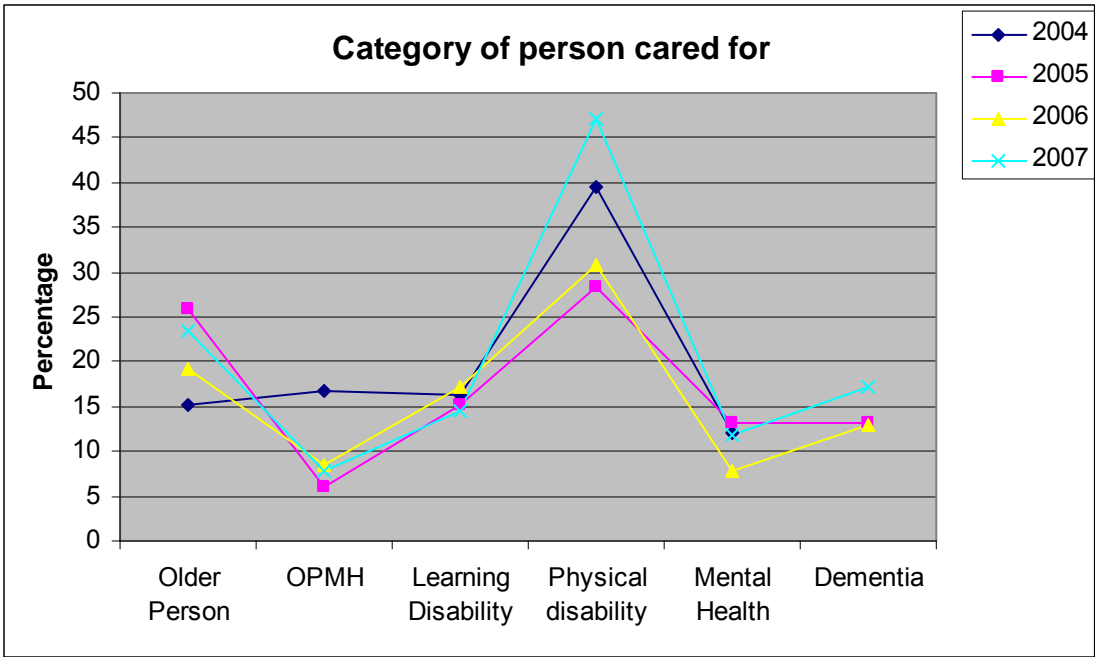


The above graph shows the largest number of cared for being in the 64 year old plus age group and this number is growing. The biggest single group is aged 75 years old plus, now representing over 60 percent of all cared for.

This is in line with the national trend of the UK population getting older. This pattern has continued and the two most recent surveys show this has risen to 63 percent, with a slight decrease in the number of very elderly but a significant increase in the number of people of pensionable age:

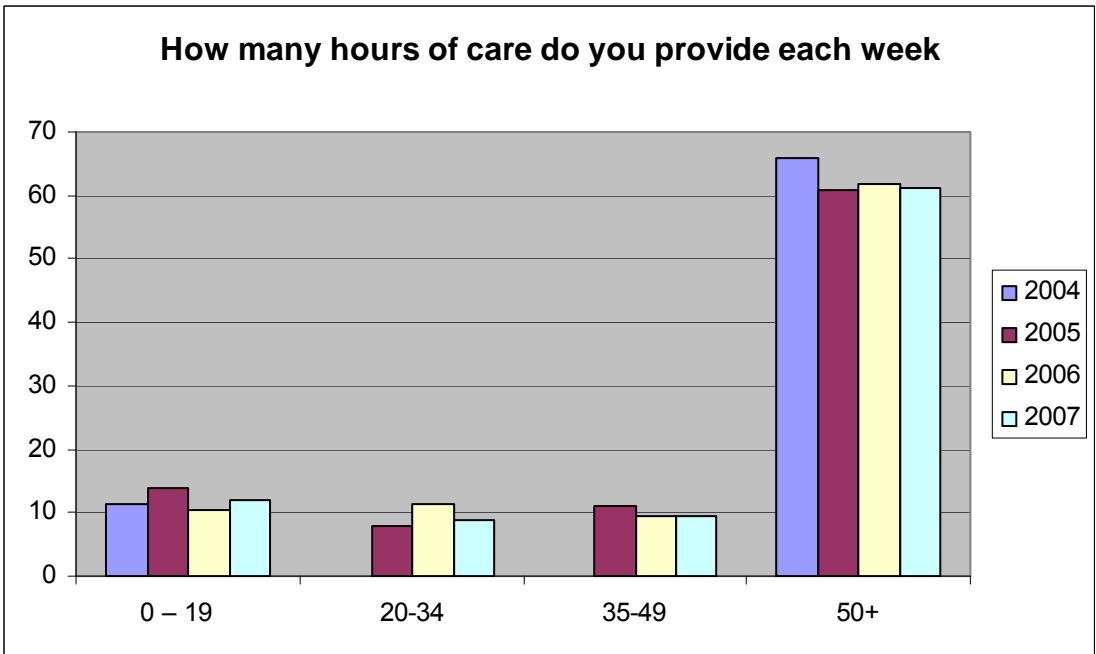
The latest survey for 2008 provides further information:

2008 carers' survey		2008
Age of person cared for	Under 18	10%
	18-24	5%
	25-34	5%
	35-44	5%
	45-54	5%
	55-64	8%
	65-74	17%
	75+	46%
No. of responses		902



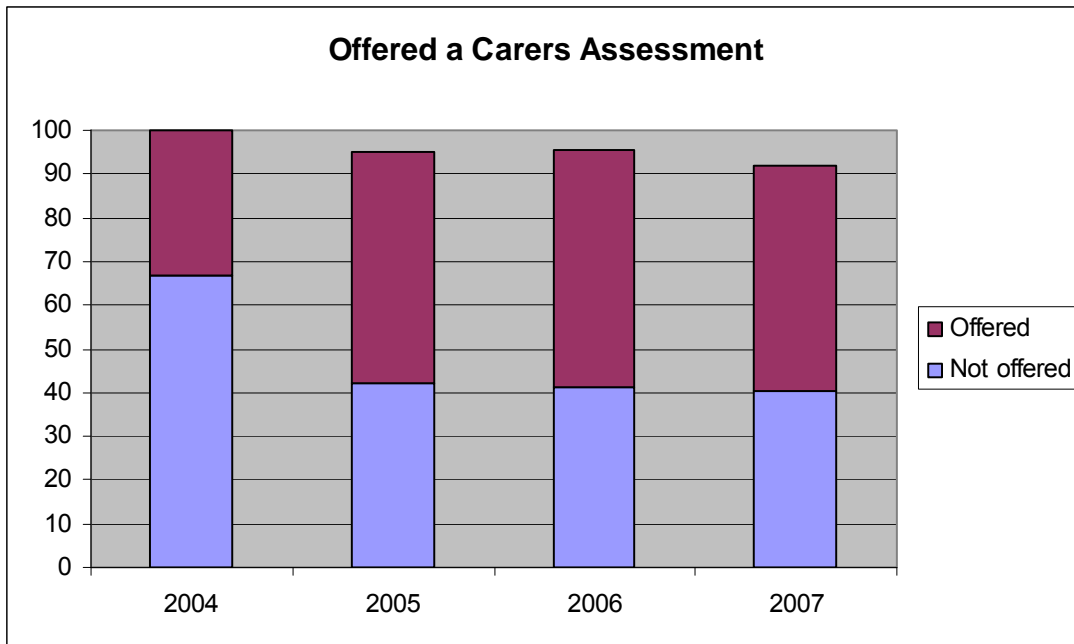
The above graph shows the largest category of person cared for as having a physical disability and it is increasing from 30 percent in 2006 to over 45 percent in 2007.

The data in this table may overlap to some extent because of the tendency of people not to categorise the person they look after as “old” but as physically disabled – see table for age of cared-for above in which 63 percent of people are 65 years old or over.



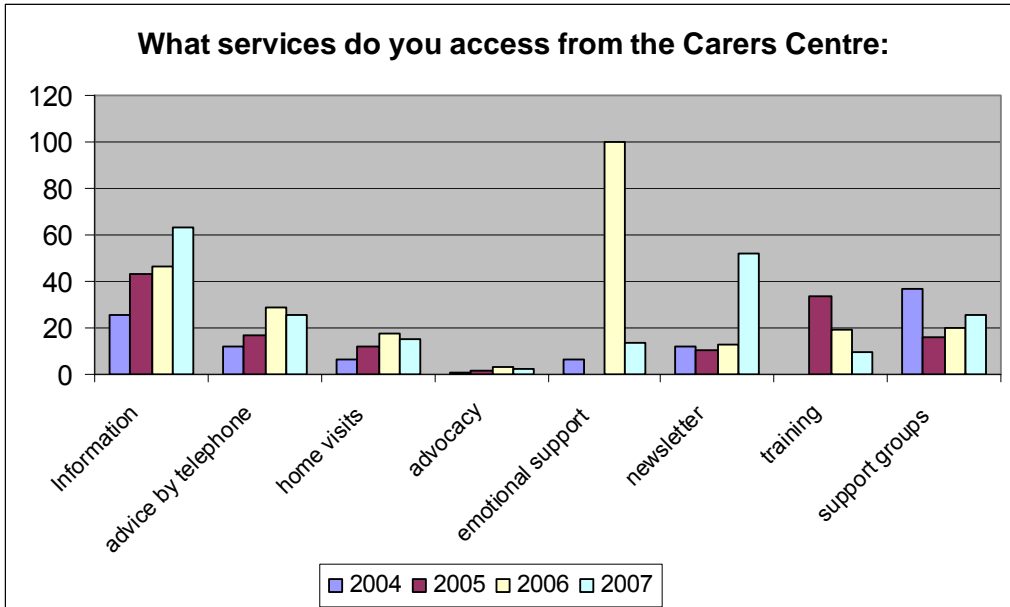
The above graph shows the most amount of hours provided within the caring role tends to be over 50 per week and this is provided by 60 percent of carers and over. This has been a constant pattern between 2004 and 2007 and has continued into 2008. The comparative figures for 2008 were:

2008 carers' survey		2008
Hours of care	0-19	16%
	20-34	11%
	35-49	14%
	50+	60%
	No. of responses	819



The above graph shows there was an improvement in the percentage of carers being offered an assessment from 2004 to 2005 when this went up from 40 percent to 60 percent - but this has since remained constant. Action is being taken to improve this and will be referred to later.

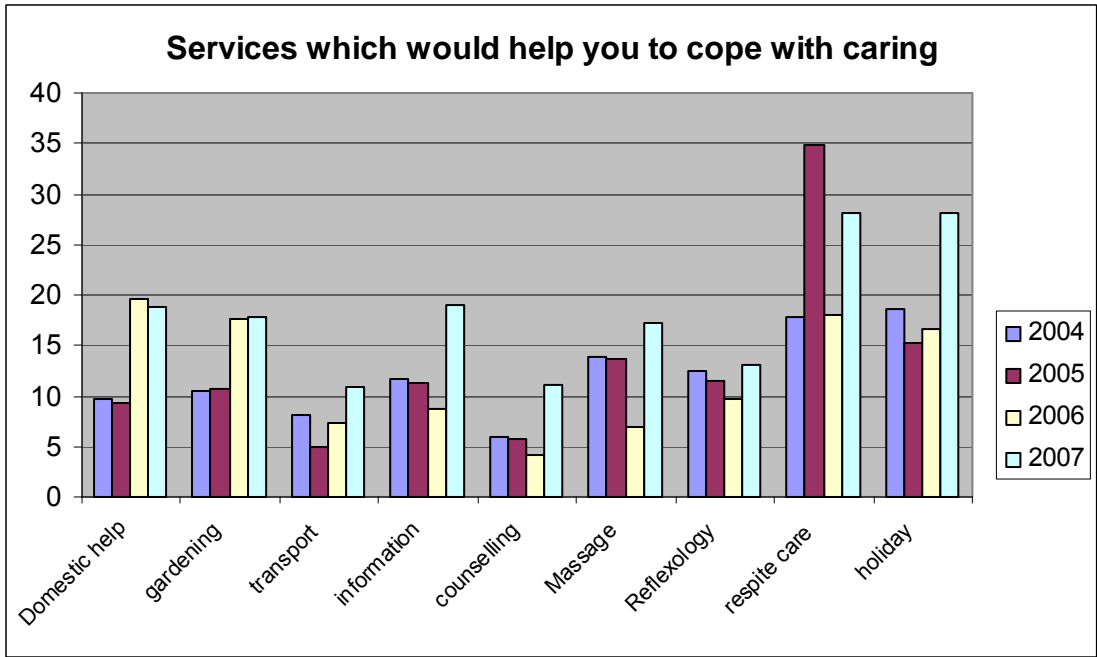
The 2008 data showed that more carers were offered an assessment which has begun an improvement that should help to maintain the recent measures taken by BCC to increase the number of assessments done.



The above graph shows a varying range of usage of the key services offered by Carers Bucks. The services are accessed from the two Carers Bucks offices within the county.

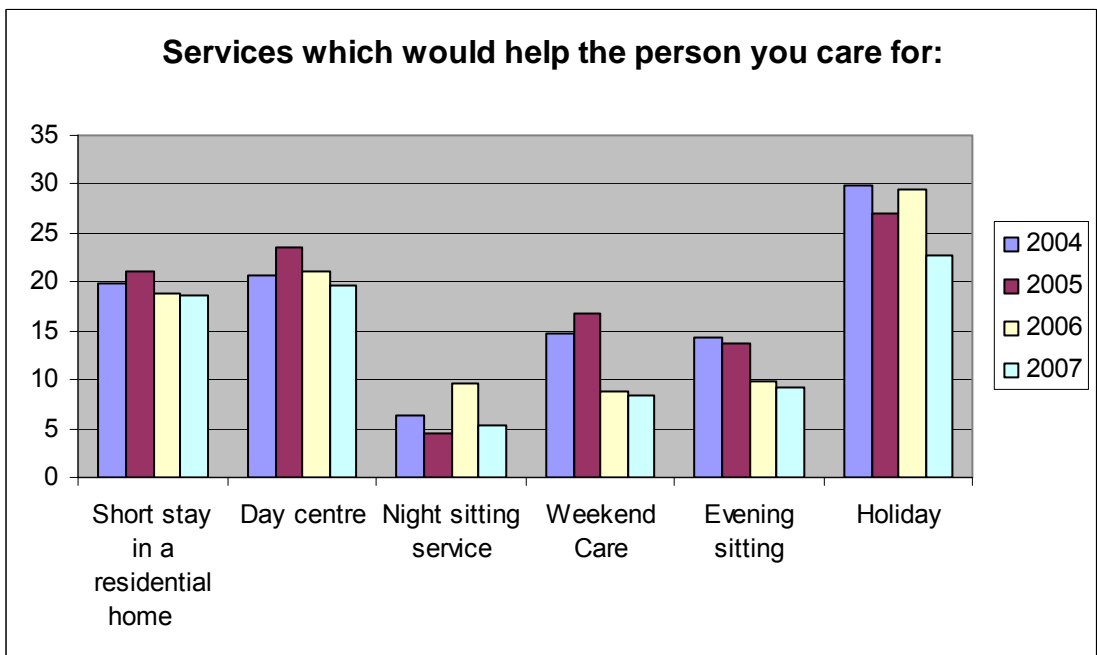
The graph shows no established consistency in the pattern of services used over the last four years and this may reflect the changing nature of the membership base of Carers Bucks. It shows, however, that advocacy was consistently the least accessed service. Advocacy is one of the contracted services for Carers Bucks to deliver and the graph suggests the need for Carers Bucks to promote more awareness of, and effort to, deliver the service. However, it may also reflect the way in which people perceive the help they have received. Often a contact that leads to advocacy work is perceived as information or advice without the carer him or herself recognising the background work that has gone into providing a solution.

The revised survey to be issued during 2010 will have more explicit questions that should draw out more useful data.



Respite care and alternative therapies are the most popular services that carers feel give them a break. This has continued into 2008:

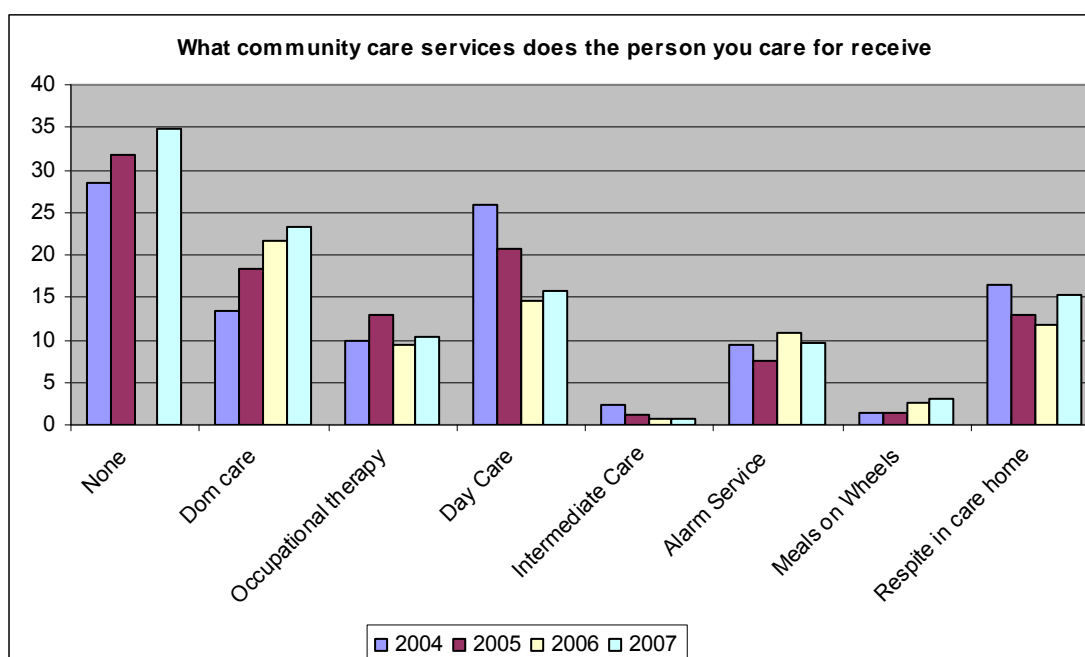
2008 carers' survey		2008
Services which would help the carer: proportion of carers mentioning each item	Alternative therapies	26%
	Respite	22%
	Gardening	18%
	Domestic help	18%
	Transport	13%
	Counselling	12%



Taking these questions together, from the last two graphs, it is clear that what most carers and persons cared-for want is respite and holidays. Holidays for those cared-for shows a consistent high level of want between 2004 and 2007. In 2008 the question was not asked in the same way but the sort of services received (where there were any) were:

2008 survey	2008
No services	27%
Personal care	29%
Day care	19%
Respite in a care home	14%
Alarm service ice	13%
Occupational therapy	9%
Meals on wheels	2%
Intermediate care	2%

Please note – these services are not mutually exclusive so the percentages will not add up to 100.



When looking at the levels of respite received by the person cared for from the above graph it shows an interesting difference to the high level of respite (in its various forms) wanted from the respondents. The graph shows, however, a high number of persons cared for receiving no community care services, this was at 27 percent in 2008 arresting an increase in previous years.

Further survey analysis has found that a key impact of caring is on carers' financial position in terms of loss of earnings, loss of promotion opportunities, giving up or

reducing work, and increased dependency on benefits or reduced income through living on pensions. All of which can diminish the quality of life that carers are able to enjoy. Carers' health and leisure opportunities also suffer. Results from the last two years include the following:

Comparison over last two years		2007	2008
Physical health of the carer	Good	36%	40%
	Fair	53%	49%
	Poor	10%	12%
	Number of responses	623	853

Comparison over last two years		2007	2008
Carer suffering from long-term illness or disability	Yes	34%	38%
	No	66%	62%
	Number of responses	599	818

Comparison over last two years		2007	2008
Carer's health made worse by caring	Yes	58%	52%
	No	42%	48%
	Number of responses	583	793

Comparison over last two years		2007	2008
Carer has suffered injury through caring	Yes	25%	26%
	No	75%	74%
	Number of responses	603	799

Comparison over last two years		2007	2008
GP / surgery knows that the respondent is a carer	Yes	85%	87%
	No	15%	13%
	Number of responses	601	818

Comparison over last two years		2007	2008
Carer has visited GP because of the effect of caring on their own health	Yes	45%	38%
	No	55%	62%
	Number of responses	602	827

Comparison over last two years		2007	2008
Activities given up or cut back since becoming a carer: proportion of carers mentioning each item	Holidays	61%	65%
	Day trips / leisure activities	65%	65%
	Nights out with friends or family	54%	54%
	Buying clothes	19%	25%
	Christmas presents	17%	20%
	Heating	8%	11%
	Buying food	9%	9%

Comparison over last two years		2007	2008
Carer's role restricts access to sport / leisure activities	Yes	65%	60%
	No	35%	40%
	Number of responses	560	785

Perhaps most significantly, in terms of lost opportunity, reduced circumstances and surrender of future earning potential, over a quarter of those carers asked in 2007 and 2008 had negative effects on their work status as a result of caring:

Comparison over last two years		2007	2008
Some changes to working lives of carers	Had to refuse or didn't apply for a job	9%	5%
	Took a lower-paid job	4%	1%
	Changed to part-time	8%	7%
	Left work entirely	18%	16%

That there is a job to be done with working carers is borne out by the number of carers receiving Carers' Allowance:

Working-age client group - key benefit claimants (May 2009)

	Buckinghamshire (numbers)	Buckinghamshire (%)	South East (%)
-			
Total claimants	25,470	8.5	11.3
Job seekers	6,870	2.3	2.8
ESA and incapacity benefits	9,880	3.3	4.7
Lone parents	3,050	1.0	1.5
Carers	2,090	0.7	0.8
Others on income related benefits	810	0.3	0.4
Disabled	2,030	0.7	0.9
Bereaved	750	0.3	0.2
Key out-of-work benefits [†]	20,610	6.9	9.4

Source: DWP benefit claimants - working age client group

Note: Key out-of-work benefits consists of the groups: job seekers, incapacity benefits, lone parents and others on income related benefits
% is a proportion of resident working age population of area

Carers represent 10 percent of the people claiming income related benefits in the county and 0.7 percent of the working population. While this is below South East and national percentages it is a significant number of people

In addition to the survey results, consultation on this strategy with the Carers' Partnership Board and sessions with carers during 2008 provided the following key messages which help in providing understanding of local needs of carers:

- The need for good quality and timely information to help carers
- The need for quality and timely financial advice on their incomes and range of benefits available to carers, including clear explanation of the rationale of the eligibility criteria concerning access to community care services
- The need for specialist support groups, particularly, for people with eating disorders and Huntingdon's Disease
- The need for clear care plans provided by care management teams which acted upon and followed through
- The need for more provision for people with severe mental health problems, so that carers can have respite
- The need for a clear definition of what defines a carer that would help to improve awareness and recognition of the caring role – particularly for GPs who needs to be more aware and responsive in recognising and helping to meet the needs of carers
- The need to reach out to more hidden carers
- The need for the ICE scheme to be more responsive to the needs of carers who have no family or neighbour to provide back-up support in emergency situations
- The need for the carer assessment process to be more transparent and clear
- The need for training targeted at agencies who deliver care services (for example: domiciliary care) that would them help to understand and respect the needs of carers more
- The need for statutory equality impact assessments to address the issues for carers
- The need to provide more support to working/parent carers, particularly for those who care for disabled children
- The need for moving and handling training for carers that would help to reduce risk of injury and health problems
- The need for carers to be more involved in providing feedback on their experiences, including case studies, that can be used to inform service reviews and future developments concerning carer services

In addition to quantitative data we are beginning to gather qualitative data via the “Making a Positive Difference” forms and an outcomes matrix form in the new small scheme contracts.

To make this an active process, BCC have set up a Carers’ Provider Forum to bring together stakeholder organisations, contract holders and potential contract holders. It is hoped that the shared knowledge and awareness will lead to mutual understanding and possible formation of partnerships, joint referrals and eliminate any duplication of effort to make limited funds go further.

7. Relating needs to supply

This section considers the scope and supply of services that are available to carers in Buckinghamshire, identifying where there are issues or gaps in terms of meeting carers' needs.

7.1 Breaks and services for Carers.

Carers receive, or benefit from, services in several ways:

- Goods or services to the person they care for that gives the carer a break (Carers' breaks)
- Goods or services directly to the carer to provide a break such as a holiday (Carer's services)

These goods and services are currently delivered by:

- Care management teams after a carer's assessment, or after an assessment has been offered and refused. This is for a carer caring for an eligible service user
- Oxfordshire and Buckinghamshire Mental Health Trust (OBMHT) through funds held by them transferred from the Area Based Grant (ABG) funding and managed by their in-house carers' assessment team
- Carers Bucks via a Bursary Fund which makes direct payments and provides various lower level services to give a break to carers
- Voluntary organisations which run small targeted schemes under contract with BCC

Provision from Buckinghamshire County Council:

Breaks and services for carers are a vital area of provision and is largely provided as a result of a carer's assessment by care management teams in the council. Breaks and services are provided in the following ways:

- Via Direct Payments to the carer or the cared-for to purchase items or services that will result in a break for the carer
- Respite via domiciliary care for the cared-for
- Respite via residential care for the cared-for

These services are funded in part from the carers' allocation in the ABG and, in part, from mainstream budgets for service users. The funding is allocated to care management teams and it has increased steadily year upon year from inception as the Carers' Grant. Recent figures suggest a shift in the way carers funding is allocated:

Year	Amount spent from main budgets	Amount spent from carers grant allocation	Total spent	Average amount spent on each carer following assessment	No. of assessments completed
2007/8	£400k*	£304k	£704k	£452	1556
2008/9	£259k*	£519k	£778k	£453	1716

*Amount identified as any period of short term care of four weeks or less being assumed to be giving a carer respite.

More money is being spent as a total and more funding came in 2008/09 from carers' funding. The original intention of the Carers' Grant was to reach hidden carers and to then integrate those carers into mainstream services. The dedicated funding is increasing. Although the link cannot be proved there is a concurrent increase in carers' assessments. Linking carers' assessments to provision of a service from carers' funding has been used as a cornerstone of increasing the number of assessments undertaken.

Breaks through the voluntary sector

The council funds a number of contracts with voluntary organizations to deliver breaks for carers, e.g. outings, holidays, items of equipment and other services. Some of these are:

- Gateway Clubs who provide a variety of breaks to Carers
- The Alzheimer's Society who deliver training and support to carers of people with dementia
- Turnstone Support who run an evening group for people with a learning disability to give their Carers a break
- Headway who provide days out to Carers and those they look after
- DrugFam who support carers and family of people addicted to drugs and alcohol

These contracts support varying numbers of carers, for example while Headway give respite breaks in the form of holidays to a small group of carers providing care to a very dependent group of people Gateway provide frequent short breaks to a large group of carers. Contracting with local organisations, whether they are particular to Buckinghamshire, like DrugFam, or branches of national organisations like the Alzheimer's Society, produces benefits and added value for carers, such as:

- Local knowledge
- Access to funding that local authorities cannot apply for
- Volunteer effort
- Charitable funding
- Client and carer base over that known to BCC

The value of these short contracts last year was over £90,000 and the Carers' Partnership Board are instrumental in deciding which schemes are recommended for funding by BCC.

A principle of service provision for carers has been to make the same services available across the county, but sometimes this has proved not to suit local need, for example:

- Turnstone Support run a group (Sunflower) for people with a learning disability in Aylesbury, this has been tried in High Wycombe, Chesham and Buckingham but while the Sunflower Group thrives in Aylesbury it has proved unworkable elsewhere.

Equally BCC has made services available in certain areas to redress an imbalance of funding, for example:

- BCC fund Gateway to provide evening activities for people with a learning disability in High Wycombe and the North of the County to give an equal opportunity to access the clubs that are funded by a benefactor for the Amersham area.

Getting information that is consistent and comparable over the years has been difficult because of the changing reporting requirements and the changing methods of delivering services.

Breaks through Carers Bucks

Carer Bucks are allocated funds by the council to use for making bursary payments to Carers and those they look after to give breaks to carers. These are provided in three ways:

- Direct payments to the carer to buy something for themselves, this could be a service or item that will make life easier for them
- Direct payments to the cared-for which also results in making life easier for the carer
- Funds being released to Carers Bucks or other organisations to run small schemes that will result in carer respite

Breaks through emergency respite

Carers Bucks administer an emergency respite scheme for carers (ICE – In Case of Emergency) who do not have cover arrangements in case they become suddenly unable to carry out their caring role. Carers Bucks will activate a care arrangement plan in these situations. The plan is agreed with the carer and the person they look after.

The scheme is funded by BCC and has given Carers Bucks a first full year target of 200 members to come under the scheme. The first full year target was not quite met with 189 completed.

One problem revealed in the first year of operation was the reluctance of people to formalise informal arrangements, this has led to a large number of uncompleted care arrangement plans – about the same number as the completed plans.

Breaks through the PCT

Buckinghamshire PCT spends almost £12.5 million on Continuing Care which includes some carer support and respite care. The PCT also spends around £620,000 on respite and continuing care for children which gives carers respite, and £84,000 on mental health carer support.

Breaks through independent agencies

There is provision outside, or in addition to, any statutory funded provision, some of which may be part-funded by grants and some of which may give carer respite that is difficult to identify but is nevertheless an important part of carer support in the way it is localised, targeted and often condition specific. This type of service is provided by the following agencies:

- Alzheimer's Society Aylesbury which provides help, support and advice for people with dementia, their carers, families and friends
- Alzheimer's Society Buckingham which provides information, advice and support for people with dementia and their carers. Monthly carers support group meetings are held as well as a monthly drop-in centre for people with Dementia and their carers. One-to-one support and advice is also available
- Amersham and High Wycombe Parkinson's disease Branch gives both emotional and practical support to people with Parkinson's Disease and their carers. There are monthly meetings, outings and a Theatre Community support worker is employed to work with branch members and non-members
- Autism Bucks runs the Spectrum Club in High Wycombe. This is a youth club for adolescents with Asperger's syndrome or higher functioning autism
- Beaconsfield Carers Support Group offer groups providing support, help, advice and information on all aspects of caring. This meets once a month and also has a telephone help line
- The Buckingham and Winslow Community Care Forum run a series of services to help the Buckinghamshire community. These include a hospital car service and a Care for Carers group
- Buckingham and Winslow Young Carers Group
- The Burnham Health Promotion Trust was set up to promote good health in the local population and to this end it initiates many projects of its own and works in partnership with others to help carers amongst other people
- There is a support group for people who have undergone laryngectomy which takes place at Amersham Hospital. Family are welcome to accompany them to the meetings

- Great Missenden has a support group for carers of people who have dementia (including Alzheimer's Disease). They give advice on all aspects of caring and of aids and allowances available. A newsletter is issued every two months containing articles on caring and updates on allowances etc.

More contact with the smaller organisations will help us to greater understand detailed needs of carers of people with highly specific conditions.

Service Gaps

This section covers known issues about the availability and supply of services in meeting the needs of carers. Consultation with care management teams and voluntary sector organizations for this strategy has helped to identify anecdotal evidence about what these issues are.

Mental Health

Mental Health professionals in Community Teams find it hard to access respite care that is local:

“I have not been very successful in using respite care for people with mental health problems. Part of the problem seems to be that the respite care is a long way away, and that you have to go for a week. Some of my clients are very anxious and would prefer something closer to home” (Mental Health Social Worker)

“Adult Services will not fund respite. The main respite centre is Forrester’s in the New Forest which is run like a holiday centre but is very expensive ... There is another establishment in Oxford but there is no specialist support and again that is rather expensive (and) is mainly for people with a severe mental illness such as depression or psychosis. ... ” recently we have had more referrals for young people with Asperger’s and a MH issue – there seem to be little or no resources for this group who have too high an IQ for LD services but have poor social skills and often challenging behaviour so parents are almost prisoners in their home” (Team Manager)

Physical and Sensory Disability (PSD)

“There is quite a lack of resources for adults with physical and sensory disabilities and they do tend to be more expensive as they are not blocked booked beds such as teams for older people may use.” (PSD Care Mgr)

“There is no specific residential respite available for young people with PD in Chiltern and South Bucks (or in Bucks?). Chiltern House in Gerrards Cross does have a few respite beds but they are often booked up well in advance. This can result in a young man with spinal cord injury being placed in a nursing home with older people if respite is required, making it much more difficult for carer/parents to have a break. I believe there was a respite resource in Amersham some years ago and this is very much missed.” (PSD Care Mgr)

“There are Vitalise holidays available and many have enjoyed Park House,(a respite facility in Norfolk) but people sometimes want to be nearer to home and with others of a similar age. Many carers would benefit from a resource specifically for them, respite or sitting service, but I am not aware of any.” (PSD Care Mgr)

“One of my client's mothers currently has a complaint in about lack of respite for her son. There are few ABI (Acquired Brain Injury) units for long term care in Bucks or nearby, and none of them offer planned respite. They have offered to let us know when they have a bed available in between permanent placements e.g. while they are awaiting funding to be agreed for a new long term resident, while this is better than nothing, it is very unpredictable as to when (if at all) they might become available.

The other gap is in agency providers who have some/any specific knowledge about ABI and the needs of the clients. We have several agencies who are good at traditional care, but struggle when it is not hands on, and where they have to supervise/provide ongoing prompting/ help clients plan and initiate activities.” (Specialist ABI Care Mgr).

HIV/AIDS:

“In regard to HIV related breaks. There are presently 2 services that I'm aware of that offer people living with HIV a respite service. These could be carers living with HIV or someone quite independent that does not require a carer. However, as more people are living much longer I predict there will be a noticeable change within the next ten years for people wanting a service like this, this maybe down to increase care needs, growing older with HIV, the chance to get away from the daily grind, but for some the chance to be able to go somewhere for a few days to access HIV/AIDS related services and not to worry about discrimination/confidentiality.” (Specialist HIV care manager)

Out of Hours:

Overnight, at weekends and on bank holidays the lack of easily available services is highlighted and is proving a difficulty for the new emergency respite scheme (ICE – In Case of Emergency) where carers do not have alternative carers that they can nominate to take over their role if they are suddenly unable to care for the person they look after.

No gaps in service were noted by care management staff working with older people. This may be because in terms of volume and ability to provide good quality services this is an easier sector to work in. This suggests that the targeting of these small areas of need for people with more acute conditions is the way in which partners should be directing their effort.

The intentions for commissioning short term care services of which respite is a part should be detailed in the individual care group strategies. Commissioners for individual care groups should be aware of the need to localise services and target small numbers of people in the most acute need.

8. Financial Resources 2009 - 2012

This section details the financial resources committed by AFW and PCT to funding services for carers. The figures shown below are the baseline for 2009 and will be subject to change for subsequent years

Item	Funds for 2009/10 '£'	What it provides
Total Carer Services funding from the Area-Based Grant.	1,555,000 in Bucks 20% to Children's 80% to AFW. 176,000 to emergency respite	20% to Children's 80% to AFW. £176,000 to emergency respite
Voluntary Sector Contracts including Carers Bucks	586,250	<ul style="list-style-type: none"> - A Carers' Service – Emotional support, health advice, general information, general advice and advocacy for Carer - An emergency care replacement scheme to give carers peace of mind when leaving the person they look after - Funding for small schemes with Voluntary and other organisations; Alzheimer's Society for breaks/outings; Gateway for breaks/outings; Sunflower Club; Headway for breaks/outings; Small schemes presented to a panel to improve the lives of carers. Current schemes planned include training in computer use and an emergency respite fund linked to ICE.
Oxfordshire and Buckinghamshire Mental Health Trust	130,000	BEST – Carer training for all groups of carers of people with mental health issues. Also provides respite care in a variety of ways.
Care Management within BCC	400,000	Split between care management teams to provide respite care for carers by extra help for the person they look after. This can be day,

residential or home care

20% of grant to Children's Services	311,000	Services for Young Carers and Parent Carers £126,000 goes to Young Carers in Carers Bucks.
5% of grant to administration in BCC and contingency money	77,750	Salaries for the Service Development Manager (Carers) and one part-time admin post, some other expenses such as conferences.
TOTAL	1,555,000	As above
*2009/10 - £1,671,000		
*2010/11 - £1,788,000		

Other sources of funding:

Source of funding and purpose	How funding is accessed or provided	Funds for 2009/10
Small grants from BCC	Through Voluntary Sector Development work	£97,000
Continuing Care (PCT)	Overall budget includes some money spent on respite care	Part of £12.5m
Respite and continuing care of children	Some of the funding for continuing care of children includes spending on respite care to give parent carers a break.	£620,000
Mental Health carer support		£84,000
Stroke funding To assist carers of people who have had strokes	From dedicated stroke grant to Carers Bucks to develop an advocacy support service for carers of stroke survivors.	£10,000
Aiming High for Disabled Children Respite care DH pilots Improve health of carers	Link to government directive to support children with disabilities and their families in three priority areas: Access and empowerment, Responsive services and Improving quality and capacity. Health checks for carers – details unknown as at October 09	Amount unspecified
Central government	Working Carers	£38m nationally but in existing budget

Central
government

Carers' Survey – pilots due to be run in 09/10,
Buckinghamshire has sent information and copy
of our existing survey to inform initial planning.

Amount unspecified

9. The Way Forward and the Five Big Ideas

From consultation and workshops held in 2009, five 'Big Ideas for Action' have been developed. The five big ideas set out the broad strategic shifts that we want to see in the way services are delivered by the end of the lifetime of this commissioning strategy.

Each big idea sets out the case for change, which draws on the earlier sections of this commissioning strategy; examples of models of best practice; the likely impact of the change on performance; how the commissioning priorities will be funded and the most effective commissioning approach required to deliver the change.

Each big idea sets out the commissioning and decommissioning priorities of action year on year. This document is a high level commissioning strategy setting out the direction of travel for stakeholder organisations. The detail behind each of the priorities will need to be developed as well as the decision making process that is required from both commissioning organisations as we work through the priorities in the document.

What we will expect to see in 2012

The big ideas set out in this strategy are similar to those objectives as set out in the National Carers Strategy for delivering the following desired outcomes for carers:

Outcome One:

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

Outcome Two:

Carers will be able to have a life of their own alongside their caring role

Outcome Three:

Carers will be supported so that they are not forced into financial hardship by their caring role

Outcome Four:

Carers will be supported to stay mentally and physically well and treated with dignity

Outcome Five:

Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes

Therefore by 2012 we will see:

- More carers being respected as expert carers
- More carers being able to have a life of their own alongside their caring role
- More carers supported without experiencing financial hardship
- More carers supported to stay mentally and physically well

- More young carers being protected from inappropriate caring and enjoying positive childhoods

Under each big idea is listed the outcome or outcomes of the national strategy it will contribute to.

BIG IDEA 1 - Improving information for carers

This will meet objectives in the National Strategy under Outcome One: 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.

We will develop a co-ordinated approach between organisations, providing carers services, to improve the range and provision of information for carers. Information will be provided in an accessible and easily comprehensible way. Access to services, advice and advocacy relies on good and timely information, making improvements in the awareness of carers also requires good targeted information that reaches into non-traditional areas such as HR departments of large employers.

Case for change

There is no standardised information for carers or agreed approach between responsible organisations on the range of information to provide. This has led to duplication of effort and of funding in producing the information between the organisations involved. Information delivery is also variable across the county.

Multi-agency cooperation and agreed co-ordination of approach is needed on producing and making available a variety of accessible and relevant information. Information must be consistent throughout the county and the range of organisations producing it must be enlarged to reflect the full spectrum of organisations working with carers.

Commissioning Implications

Year 1

- Form a multi-agency information sub-group (ISG) to develop an information and communication strategy
- Work with all partners to standardise information to ensure the same message is going out from all organisations
- Implement information strategy
- Assess the effectiveness of traditional and new ways of delivering information

Year 2

- Review information strategy and adjust in the light of experience and new priorities identified

BIG IDEA 2 – Improving recognition for carers

This will meet objectives in the National Strategy under Outcome One: 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. This also relates strongly to Big Idea 1 and the reliance on information at key points in the system

The case for change

It is part of the new National Strategy for government to promote recognition of carers and to define an accepted term for carers. Locally we will do this by challenging the misuse of the word “carer” and integrating the need for greater recognition of the carers’ role within the information strategy. The need for recognition of the carer as a partner in care was underlined by local consultation events. Regular comment from carers stated that their experience of the carer’s assessment was that it was not treated as a dynamic document and that they were not consulted enough in the care planning and review process.

Commissioning Implications

Year 1

- Commission training to raise awareness among workers across health and social care on their responsibilities toward carers
- Undertake initiatives with those responsible for facilitating participation to ensure carers have full representation on decision making and advisory bodies within statutory organisations
- Develop actions to improve processes within care management teams that will increase the number of carer assessments, produce more clearly defined care plans and regular reviews
- Work with Carers Bucks to shift the emphasis of work with working carers to reaching large employers to enable them to develop carer-friendly policies and be aware of the carers in their workforce.

Year 2

- Undertake actions to ensure systems that identify and support carers who visit GP surgeries and medical centres are working
- Continue to commission training to be delivered to GPs and front line health workers within PCT’s community services
- Review the impact of the health worker awareness training
- Review the impact of the working carer initiatives

BIG IDEA 3 – Improving support for carers

This will meet objectives in the National Strategy under Outcome Two: Carers will be able to have a life of their own alongside their caring role; and under Outcome Three: Carers will be supported so that they are not forced into financial hardship by their caring role; and under Outcome Four: Carers will be supported to stay mentally and physically well and treated with dignity

The case for change

We need to build on previous successful work in supporting carers by providing a more integrated response from organisations to support more carers. A foundation of support has been laid down with the funding of a single carers centre which is now well known and respected. This provides a platform for other organisations to follow by learning lessons from others and improve or develop policies and projects to support carers through their organisations in a more co-ordinated way

Commissioning Implications

Year 1

- Set up a training group with all providers of training to develop a carers training syllabus and prospectus aimed at current and new carers and including those from BME groups
- Develop new support groups for BME carers and maintain current groups but with improved attendance
- Continue, in conjunction with OBMHT and Carers Bucks, the BEST training for carers of people with a mental health issue
- Continue with the cross-organisation training programme including the Alzheimer's Society coordinated sessions
- Develop a plan with the PCT to look at ways of improving the health of carers, including the offer of annual health checks
- Develop a joint plan for improving the quality, choice and availability of carers breaks
- Develop and promote ways to support working carers in maintaining their employment, including information/support that can be provided through the Council and NHS
- The Council and the PCT to review their own employment policies to identify ways in which to make their respective organisations more carer friendly
- The Council's Welfare Rights Service and Carer Centres to maximise carer income / reduce carer expenditure through advice/information/signposting on financial matters
- Develop a plan with carer organisations to provide better support for older carers during bereavement

Year 2

- Review training syllabus
- Develop new support groups for BME carers and maintain current groups but with improved attendance
- Continue, in conjunction with OBMHT and Carers Bucks, the BEST training for carers of people with a mental health issue.

BIG IDEA 4 – Improving independence and life chances:

This will meet the objectives in the National Strategy under Outcome Two: Carers will be able to have a life of their own. We will initiate opportunities for carers to have a life of their own and to make it possible for carers to take up those opportunities.

The case for change

Carers have been well supported in many ways in Buckinghamshire since the launch of the first carers' strategy in 1999, but until recently the emphasis has been on the carer as provider for the cared-for. Local evidence from surveys and engagement through carer organisations indicates that carers are missing out on opportunities to develop as people and to pursue careers, training and education. Younger people are facing lifelong consequences of missed training and education, people in midlife are missing out on promotion or career advancement and older people are having their days of retirement taken away from them. There is a need for more support to carers to enable them to overcome the inequality that their role puts on them.

Commissioning Implications

Year 1

- Provide a comprehensive programme of carer respite opportunities available to relieve carers periodically of their caring responsibilities
- Develop new partnerships with Job Centre Plus, employers, District Councils, educational establishments and leisure providers to extend the possibilities for carers to have a life outside caring
- Raise awareness of carers and the help that employers can give to them by simple work and working hours adjustments. This is linked to the general recognition of carers in the community both by themselves and others
- Learn lessons from existing successful schemes in the Hospitals Trust and OBMHT in supporting carers with developing their educational, working and training opportunities

Year 2

- Review progress and continue with successful approaches.

BIG IDEA 5 – Improving independence and life chances for young carers:

This will meet the objectives in the National Strategy under Outcome Five: Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.

This may include:

- To improve the lives of disabled young people and their carers by embracing the requirements of the national Aiming High programme
- To develop a strategy in partnership with parents, carers and other agencies to extend the range of short break care
- To ensure carers shape the services they receive within individual care plans
- To reduce the impact of poverty on families caring for a disabled child or young person
- To work with schools to raise awareness of young carers' issues

Special emphasis will be placed on the need for Young Carers to be free of inappropriate levels and types of care and to have the same life chances at their crucial development stages.

Summary

Our five “Big Ideas link the evidence of local need with the five outcomes of the National Strategy, to make life better for carers:

- We need to communicate a clearer statement of the unique value of carers and the need for services to support them. This needs to reach professionals at the point at which they meet carers, for example – surgeries, hospital wards, service user assessments and in job centres.
- We need to develop outcome-measuring tools for local services to generate and collect evidence not just to report performance but to influence commissioning activity
- We need to encourage carer participation beyond Partnership Boards and facilitate carer empowerment
- We need to change the self-perception of carers as being at the bottom of a “care hierarchy” which sees consultants at the top, primary care staff and GP’s next followed by social care professionals and the carers.
- Our strategy must acknowledge that carers in Buckinghamshire are no different from carers over the rest of the UK in being the biggest single provider of care in the country.

The desired outcomes will also meet requirements and aims under the new national strategy as shown above and will be measurable by contract monitoring, county-wide surveys and analysis of targets set by government for statutory agencies to meet.

Individual satisfaction can be measured by the “Making a Positive Difference” returns (see Appendix 2) and the contracts for services will have an outcome matrix (see Appendix 3) to measure the performance of the organisations against the objectives above.

The degree of success of the overall commissioning plan which will be developed alongside this strategy will be determined by monitoring of the plan carried out by the Carers’ Partnership Board (CPB). The terms of reference for the CPB (see Appendix 4) may need to be revised to reflect this close monitoring role. Groups may be set up to coordinate actions to achieve outcomes in individual elements – for example, it has been identified that an information sub-group is needed. If the need for other groups becomes apparent the CPB will determine the structure, membership and remit of these groups.

Other legislation relevant to carers:

Disabled Persons (Services, Consultation and Representation) Act 1986 requires a local authority during an assessment of a disabled person aged 18 or over, to take into account carers' abilities to continue caring.

Children Act 1989: Guidance to the Act reaffirms that some children will be considered as children in need as a result of the effects on them of a parent's illness or impairment. Such children will be those who have caring responsibilities and who, as a result, cannot achieve a reasonable standard of development without support

The National Health Service (NHS) and Community Care Act 1990 had as a key objective to ensure that service providers make practical support for Carers a high priority. It obliged local authorities to consult with users (the person being cared for) and carers, involving them in how needs are assessed and services are planned.

The Work and Families Act 2006: This extended the right to request flexible working to carers of adults from April 2007. The Act's main intention for carers was to "widen the scope of the existing law on flexible working to enable more people with caring responsibilities to request to work flexibly". The Act did not confer rights in any sense other than to "request". To some extent this could have been done under many organisations' existing flexible working policies. The requests can be legitimately rejected on the grounds of organisational need.

The Disability Discrimination Act (DDA) 1995: The Sharon Coleman case demonstrated the value of a rights-based approach to achieving fair treatment when she took her employers to the European Court to establish the concept of "associative discrimination". While the DDA provides no specific rights to carers this act was used to give a right to a carer to have flexible working. This may prove a stronger method of rights enforcement in the future rather than applying under the Work and Families Act. The right to request flexible working to care for a child had been extended to parents of disabled children up to the age of 18 under the Employment Act 2002 – for able children the qualifying age was 6.

Community Care (Delayed Discharges etc.) Act 2003 confirms the right of carers to have their needs assessed as part of the assessment of needs of a person who may require a community care service to achieve safe discharge from hospital.

Making a Positive Difference

EXTERNAL ORGANISATIONS: MAKING A POSITIVE DIFFERENCE

Have you made a difference for your client?

Please let us know how our services have positively affected a client, a carer or maybe a group.

It only takes a couple of minutes to complete this form. The information you give will not only highlight good practice but will help us learn from your experiences and help monitor and develop the services we provide.

If you have any questions about the information requested below please contact Bev Frost on 01296 382173.

Your name:		Tel/Ext. no:	
Organisation:		Date:	

Who? <i>(Client/Carer's name)*</i>
What? <i>(Team/service include all service(s) received)</i>
Where? <i>(Locality)</i>
Why? <i>(The issue – e.g. client discharged from hospital and cannot cope at home)</i>
Story: <i>(Outline of client's circumstances, and the services provided)</i>
Outcome: <i>(based on effect of services, provided. If available, please include any feedback or quotes provided by the service user)</i>

*Client information will be held in strict confidence and used anonymously for reporting purposes. However, in order to promote and inform our Buckinghamshire residents of the services we can provide it would be helpful to let us know if your client would be willing to be contacted for further information.

Yes
No

Thank you for completing this form.

Please return to Chris Reid, 11th Floor, County Hall,
Walton Street, Aylesbury HP20 1YU or via email to wfox@buckscc.gov.uk



Outcome-based Contract Matrix

	<p>Quantity</p> <p>Number of carers receiving respite</p> <p>Number of breaks</p> <p>Number of hours of respite</p>	<p>Quality</p> <p>Did carers feel this was the best way of delivering support?</p> <p>Was the support timely?</p>
<p>Effort Effect</p>	<p>Was there an increase in attendance generally?</p> <p>Was there an increase in attendance when the outings were offered?</p>	<p>Did carers report a benefit – have you measured this in any way?</p> <p>How many carers have been included on the “Making a Positive Difference” (MAPD) forms?</p> <p>Have any carers individually filled in a MAPD form</p>



CARERS' PROVIDERS' FORUM.

TERMS OF REFERENCE

Purpose:

- To enable contract holders to report on progress with their schemes (spend, numbers of breaks provided, carers assisted, beneficial outcomes etc.)
- To provide a networking opportunity and make providers aware of the work of others
- To provide partnership development opportunities
- To share knowledge and good practice
- To enable Buckinghamshire County Council (BCC) to report on developments in policy and practice within government - local and national
- To outline guidelines for bidding for future funding
- To pursue the intentions of and carry out work under the carers' strategies - local and national
- To enable BCC to identify market gaps to inform future funding decisions

Constitution:

1. The forum will ordinarily be convened and chaired by a member of Buckinghamshire County Council Commissioning staff. The Board will consist of representatives of existing or potential statutory and voluntary sector organisations holding contracts or service level agreements to deliver services for Carers.

2. There will be a quorum of four members of which at least one will be from each of the voluntary sector and BCC.

3. Meetings will be open to guests by prior arrangement.

4. Frequency of meetings:

The Forum will meet every four months in the offices of the holder of the carers' services contract (currently Carers Bucks) with Buckinghamshire County Council.

Review of the forum

The purpose and constitution of the forum will be reviewed every twelve months.