

Caring About Carers

Review of Support Services for Carers in Bracknell Forest by a Working Group of the Social Care and Learning Overview and Scrutiny Panel



August 2008

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1. Foreword by the Lead Member

- 1.1 Carers provide a vital service to thousands of our most vulnerable Bracknell Forest residents. Carers often feel very isolated - many caring for 24 hours a day, most of the year and with very little time of their own. The direct benefit they have on the health and well-being of people needing care services can be profound, and through their efforts, the taxpayer is saved millions of pounds every year. Bracknell Forest Council (the Council) has a legal duty to support carers.
- 1.2 The Working Group was set up to review the range of support offered to carers and to identify gaps in provision.
- 1.3 Definition of a carer 'A Carer is someone, who, without payment, provides help and support to a partner, child, relative, friend or neighbour, who couldn't manage without their help. This could be due to age, physical or mental illness, addiction or disability.'¹
- 1.4 The Working Group comprised:

Councillor Mrs Shillcock (Lead Member) Councillor Simonds Councillor Turrell

¹ Source: Princess Royal Trust for Carers

2. Background

- 2.1 The Council's former Adult Social Care and Housing Overview and Scrutiny Panel considered a list of potential themes to be reviewed in detail by working groups of the Panel during 2007/08 to complement its ongoing work. Having considered the relative merits of seven suggested review topics, the Panel, which was subsequently re-structured to form part of the Social Care and Learning Overview and Scrutiny Panel, decided that its 2007/08 work programme would consist of reviews of the following topics by working groups:
 - Support for carers
 - Social care modernisation agenda
 - Care homes

This report records the outcome of the Working Group established to undertake the review of support for carers.

- 2.2 The Working Group welcomed undertaking a piece of work in respect of carers in order to ascertain the number of carers in the Borough, the nature of their problems and needs and whether they were adequately supported. It noted that some carers were children, falling in to the age category of five to sixteen years, whilst others were often elderly partners of those being cared for. The Commission for Social Care Inspection (CSCI) had found in its inspection of the Council's Older Person's Services in 2006 that when carers were known to the Council and aware of available services, they received good support. However, many were unaware of the support that the Council could offer and possibly did not consider themselves to be carers. It was the latter group that the Council needed to engage.
- 2.3 The work programme was subsequently agreed by the Overview and Scrutiny Commission, the parent body of the Panel, following consultation with the Leader and Chief Executive of the Council.
- 2.4 The purpose of the review of carers support has been to explore the nature and range of information describing services available to carers; to assess the accessibility of services to support carers; and to examine the delivery and quality of services to carers.
- 2.5 Key objectives of the review have been to evaluate the support to carers provided by the Council, the Carers' Forum, Bracknell Forest Voluntary Action (BFVA) and other agencies; to track the care assessment process; to identify any gaps in services to support carers and address solutions; and to assess the quality of services and support provided.
- 2.6 The scope of the review has been to obtain information on the services available to support carers; to gain an understanding of the carer support process; to consider methods of engaging with hard to reach carers; and to review the social care support to carers.
- 2.7 It was considered that a review of the support for young carers and parents who care for children with learning disabilities should not be included as it was expected that their needs would be very different.

- 2.8 A number of witnesses, both internal and external to the Council, were invited to meet the Working Group to assist with the review. One site visit and an opportunity to meet with carers were also arranged.
- 2.9 The Working Group is aware that there are a number of small support groups and local branches of national organisations. These groups, such as stroke clubs and the Alzheimer's Association, offer respite, help and advice, talk shops, coffee mornings, lunches and self-help. The Working Group acknowledges that it has not been in contact with representatives of all relevant voluntary sector organisations.

3. Investigation, Information Gathering and Analysis

- 3.1 The census undertaken in 2001 identified 8,278 carers in Bracknell Forest in the following categories:-
 - 6,230 carers providing 1 19 hours care per week (per person)
 - 676 carers providing 20 49 hours care per week (per person)
 - 1,372 carers providing 50 or more hours care per week (per person)
- 3.2 Since 1995 governments have recognised the value of the work carried out by carers. A number of Acts have been produced placing responsibilities on local authorities. In 1999 a national Carers Strategy was launched and this has been updated recently (July 2008), a précis of which is attached to this report at Appendix 2 for information.
- 3.3 The Working Group's attention has been drawn to Bracknell Forest's Joint Strategic Needs Assessment (JSNA) 2008 which is a new statutory process for which Primary Care Trusts (PCTs) and local authorities are responsible. The purpose of the JSNA is to identify current and future health and wellbeing needs of the local population, and to use this information to help plan local services. The JSNA process is not intended to highlight where current services are succeeding, but rather to discover how the local population could benefit from improvements in future.
- 3.4 A draft Bracknell Forest JSNA 2008 has been prepared and includes the following three issues relevant to carers:-
 - (i) Reduce health and social inequalities for carers;
 - (ii) Improve carers' access to services; and
 - (iii) Improve availability of advice to carers.

Although issues (i) and (ii) have not been addressed by the Working Group as they fall outside the scope of its review, it has looked at and made recommendations around (iii).

3.5 The Working Group commenced its work at a meeting with the Chief Officer: Adult Social Care in November 2007 to scope the review of services for carers. It has met on eight subsequent occasions to interview Adult Social Care officers involved in the support of carers and their cared for, the Director of BFVA, the Chairman of Carers UK (Bracknell Branch), the Council's Pensioners' Champion and to meet a group of carers at a 'Carers Tea Party' before a further meeting with the Chief Officer to consolidate the information received to date and agree the way forward. A further group of carers was invited to meet the Working Group and a visit to Age Concern's Worlds End Day Centre was arranged to enable the Working Group to explore services provided there. The outcome of the Working Group's investigation and information gathering is summarised below.

Scoping Meeting with Chief Officer: Adult Social Care

3.6 Whilst scoping the review with the assistance of the Chief Officer: Adult Social Care, the Working Group learned that there was a Carers' Forum, the administration of which was supported by the Council. The Forum met at two monthly intervals and organised quarterly Carers' Lunches. These provided information and advice for carers. The Council provided support to carers by offering respite care, some of which was delivered through BFVA. The Council provided financial assistance in the form of the carers grant to BFVA / Carers UK to support carers in the following amounts:-

2006/07 - £130k 2007/08 - £138k 2008/09 - £143k

- 3.7 The Working Group was advised that the Council block booked a bed in a private care home to offer respite care and services provided at Waymead Short Term Care Unit were being developed to make them more amenable to those receiving respite care.
- 3.8 Members ascertained that carers could access services by approaching the Council directly, through the Carers' Grants Panel or via general practitioner (GP) referral. Council services were measured against performance indicators which sought action within 48 hours of first contact with a new client and complete assessment of services was required within 28 days. At the time of the meeting, the Council was achieving performance in the highest band against these indicators. A regulatory framework applied where carers received Council services and / or purchased services registered by CSCI.
- 3.9 A study of those with physical disabilities in receipt of Council or private services had indicated that the majority were satisfied with the services received. Other work undertaken featured contact with Black Minority or Ethnic (BME) groups such as the Indian community. This included the establishment of specialist day care at Heathlands Day Care Centre for the Indian community featuring refreshments and showing Indian language films. Work with the Nepali community was currently being undertaken and if the Indian initiative was successful it could be repeated with a Nepali theme in Sandhurst for that community. Although work with the Nepali community representatives to explain the care process and would seek feedback on service needs. The Council is required to report on the provision of services to BME communities.

Information Received from Adult Social Care Officers of Bracknell Forest Council

3.10 Adult Social Care has five specialised teams providing services for those people needing care. The Working Group looked at this provision because it was seen as 'a first priority for carers'.

Older People and Long Term Conditions Team

3.11 Client groups were divided into specialist teams and this team worked with older people and those with physical disabilities, chronic / long term conditions and frailty. These clients were also divided between short and long term teams.

The short term team supported people at home during the first six weeks following discharge from hospital. The long term team, staffed by social workers and occupational therapists, then provided ongoing care where needed. The care managers (social workers and occupational therapists) were trained in both social and psychological functioning and concentrated on the social care of people in every day life. Occupational therapy specialised in provision of equipment and adaptations to assist people in the home and promote their independence.

- 3.12 New client contact and re-contact was via the duty desk in the short term team and led to needs assessment and allocation to either the short term or long term teams depending on need. Clients were regularly re-assessed to ensure that changing needs were met and cases were allocated to a team member who acted as their care manager until there was no further need for regular involvement. Care managers undertook the initial assessment of their clients and where there was no allocated care manager, the team aimed to undertake an annual review of clients' needs. Clients were able to request earlier reassessment when they felt it was called for.
- 3.13 Respite care was provided at a number of day and residential care venues including Ladybank Residential Care Home, Bridgewell Centre, Heathlands Residential Home and Day Care Centre and Downside Day Centre. Ladybank was a resource for care of older people offering long term residential accommodation with one bed bookable for respite care and an intermediate care facility known as the Bridgewell Centre which included non-bookable emergency respite care provision. Heathlands was a residential care home for elderly people with permanent beds and a purpose-built day centre that catered for mentally infirm clients. The day centre was open 7 days a week and provided a number of activities and services. It also provided night care support on three evenings per week. Downside Day Centre was accessible to the whole community and provided information, advice and opportunities to break down the barriers that existed between disabled and older people and those who are able-bodied.

Community Mental Health Team - Older Adults

3.14 The Manager of this team advised that it worked with older people suffering from dementia, mental health or depression and their carers and with younger people with dementia, the youngest of which was 49 years of age. The team currently comprised four community psychiatric nurses, two social workers, an assistant care manager and a community support worker. A further community psychiatric nurse and community support worker were being recruited. A referral assessment process was in operation and the occupational therapy services provided by the long term team were utilised where necessary. This team undertook assessments and reviews in a similar manner to that pursued by the Long Term Team.

Community Mental Health Services Team

3.15 The Working Group was advised that this team, a joint health and social care team, worked with those from the age of 16 years if out of school and there was no upper age limit. 550-600 cases were open at the time of the meeting. Intensive crisis management consisted of twice daily contact during the first 6 – 8 weeks following an episode of mental ill health. Those with longer term mental health disorders such as severe depression and schizophrenia were re-

assessed every six months and received weekly or monthly visits depending upon need. Where those aged between 16 and 18 years were concerned, the team worked closely with Child and Adolescent Mental Health Services (CAMHS). Early intervention was employed at the first sign of a mental health condition and support was offered where early indications of psychotic behaviour were displayed. Following treatment by CAMHS, clients were referred to this team and the small number of referrals from elsewhere were mainly via GP practices or schools. Early intervention also featured a watching brief involving 18 residential clients at Glenfield House and others at home or in homes in the community with support. The team was resourced with 50 staff working in a range of different disciplines.

Learning Disabilities

- 3.16 The Development Manager explained that the Learning Disabilities team was a joint health and social care team consisting of 40 staff including two assistant managers, one with a health service background and the other from Adult Social Care; team leaders; psychologists; social workers; speech and language therapists; and psychiatrists. At the time, 360 clients were known to the team excluding transitionary ones. One social worker focused on the transition from Children's Social Care to Adult Social Care working jointly with people aged 14 years plus. A yearly review of the people receiving support was undertaken.
- 3.17 Encompassing support was provided for carers of all ages and it was recognised that different age groups of carers had different needs e.g. some younger carers needed to be in employment. Enabling carers to lead a normal life was the object of their support and the Carers' Opportunities Act placed the onus on local authorities to provide the necessary services.

Short Term Services Team

3.18 This fully integrated team was funded jointly by Bracknell Forest Adult Social Care and Berkshire East PCT. The team was staffed by 90 who were split into various sub-sections of social workers, therapists, Intermediate Care support workers, intermediate carers and medical and GP cover. Both domiciliary and residential support were provided, the latter in the Bridgewell Centre housed in the Ladybank building. At the time of the meeting, there were 72 domiciliary care places and the number was growing leading to growth in the team. There was a single point of access for all referrals and the majority were referred to the Short Term Team before being signposted on to other teams if necessary. The team catered for anyone over 18 years of age and aimed to improve the quality of life by promoting independence and assisting people to remain in their homes. Although the onus was on people to access necessary care, there was a vast range of communication to inform the public of available services which were advertised via the Council's website, leaflets and other forms of publicity such as the Council's Town and Country publication distributed to all homes in the Borough. Many contacts and referrals were received from GPs, district nurses, hospital trusts and relatives or self referrals were made. Front desk staff were familiar with services and were able to screen clients and refer them to the appropriate sector of the service.

Provision for Carers

3.19 The Working Group established that carers were entitled to support where the person they were caring for was eligible for local authority services. In order to

establish this, an assessment of the receiver of care was necessary and assessment was often sought by the carer who would be involved throughout the assessment process. An assessment of the needs of the carer was also made to establish how caring affected the carer's life and determine the support required such as respite care, financial advice or other information. Allocated care managers had a responsibility to offer and provide carers with an assessment and carers could self assess via a Carers (Needs Assessment) Questionnaire. Respite care was intended to be in the form which most benefited the carer and included home support, private care, the voluntary sector, day centres, day companions and PCs for home shopping. Demand for respite care increased at weekends and during school holidays. People with learning disabilities could receive day support at Day Services (formerly known as the Bracknell Resource and Opportunity Centre) although the reprovision of day services and use of Waymead Short Term Care Unit, which offered 8 beds for respite care, was under consideration to identify service improvements. Day facilities, which were available for all client groups, were being modernised and moving away from building based activities towards accessing mainstream facilities such as community centres and leisure services using direct payments.

- 3.20 The Head of Older People and Long Term Conditions advised that the Council listened to and consulted with carers, engaged with organisations including Carers UK (Bracknell Branch), BFVA and the Alzheimers Association and fostered links with the community through Carers' Lunches and Conferences to promote services available to support carers and access hard to reach groups. Feedback from carers, which featured many compliments, was also received via the Pensioners' Champion, Councillor Cliff Thompson, and Barbara Briggs, the Chairman of Carers UK, and all issues were fed back for resolution.
- 3.21 Carers were encouraged to specify whether they were in need of less or greater help and care managers worked closely with the families of those in need of care. An overnight service was available at Heathlands Residential Home to give carers a 24 hour break and a Government grant of £32k enabled emergency respite care to be provided in an event such as a carer being taken ill. Although initially some carers were reluctant to hand over care in order to have a break from caring, once they had received some intermediate services they became accustomed to, and grew to appreciate, regular respite support.
- 3.22 The quality of carers' services was measured via quality questionnaires and annual reviews and feedback was received through the Carers' Lunches and Conferences. Regulations required quality monitoring of home support, which all external providers were obliged to carry out, with a view to promoting good practice. Bracknell and Wokingham College ran some courses directed at carers.

A Strategy for Supporting Unpaid Informal Carers

- 3.23 Resources for respite care were made available by the Council to enable carers to attend the quarterly Carers' Lunches which provided opportunities for information exchange and socialisation. A Carers' Conference was held every two years and was well attended. The next would be held in 2009. The Conferences were themed and topics for inclusion were suggested by carers.
- 3.24 A Carers Strategy Group was set up in 2005. Membership consisted of representatives of BFVA, Adult Social Care, the PCT, the voluntary sector and carers. The purpose of the Group was to develop a Carers Strategy. The

Strategy was now in draft form and included an Action Plan. It was the Group's intention to take this draft document to the Carers Forum in September for consultation. It was then expected that the Strategy would be signed off by all organisations involved in its preparation and delivery. In the Council's case, the Strategy would go to the relevant Executive Member for his support and agreement.

- 3.25 One of the outcomes of the Strategy was the decision to update the Carers' Information Pack and this was currently in hand. The pack would contain contacts for carers' organisations and support groups and for Adult Social Care in addition to information relating to services for carers, benefits, rights, health and wellbeing. The packs would be in a loose leaf format to facilitate updating and when complete copies would be sent to GP practices, Adult Social Care, BFVA, the Patient Advice and Liaison Service, support groups, practice nurses via the PCT and displayed in relevant places.
- 3.26 This year BFVA have set up a Carers' Information and Support Group who plan to meet regularly to provide additional opportunities for information exchange.

Information Received from Bracknell Forest Voluntary Action (BFVA)

- 3.27 Martin Gilman, the Director of BFVA, outlined the organisation's involvement with carers in the Borough and explained the role of the Carers' Services Manager, who oversaw the carers' grant allocation process, offered increased support to carers and undertook related development work. The Working Group received copies of the draft Carers' Strategy; Carers' Services, Business Plan and Costings 2008-2011; the Carers' Services Manager's job description; and information leaflets for carers which were displayed in GP practices and public locations around the Borough.
- 3.28 BFVA also had an Adult Carers Development Worker who concentrated on offering support for carers through events and training. She worked closely with BME communities and was commencing work with the PCT to provide a carers' training pack with care, handling and medical aspects. The support criteria for carers had been widened and included respite care hours. Direct Payments could be utilised and although respite care had typically been for one hour per week previously, this had now been increased to two hours or more to widen carers' respite activity options. Many carers sought to pursue hobbies, interests and travel as a form of respite and utilised their carers' grant for this purpose.
- 3.29 The Working Group was advised that the delivery in Bracknell Forest of the carers' grant from central Government was unique in the country in that it was delivered through the voluntary sector, namely BFVA (the amounts are set out in paragraph 3.2). This had occurred as five years previously there had been an issue of how funds reached carers and as the voluntary sector had links and contacts with carers it was considered appropriate for BFVA to deliver the grant. A Carers Grants Panel controlled this process and grants were allocated to carers on application on a monthly basis and approximately 150 carers received a grant for respite care in total. The carers' grant was used towards funding short beaks for carers. All grant applicants were required to produce references from a social worker, GP or similar professional. Careful checks were made before grants were released and assistance with grant applications was offered where needed. Careful financial management ensured that there was a little funding remaining at the year end and any surplus was carried over to the following year.

- 3.30 Although the census in 2001 had revealed that there were 8,278 people registered as a carer in Bracknell Forest, the majority of whom were part time carers, this number was likely to have increased over the last seven years. There was national recognition of the amount of spending carers saved the tax payer which was estimated to be in the region of £87m per annum.² As at October 2007, BFVA had 191 carers on its database. In addition to BFVA and the Council, a significant number of other groups provided support and services to carers. Many carers did not wish to access services as they were content to remain independent, did not consider themselves to be carers or wished to avoid what they perceived as interference.
- 3.31 The receipt of a lottery grant to reach those carers in most need who were not accessing support was welcomed and work in this area would now be pursued following the recent appointment of a new Carers' Services Manager.
- 3.32 The amount of information regarding carer support services in the public arena had increased during the last 9 to 12 months and included leaflets, press articles, Carers' Lunches and the DVD 'My life as a Carer'. Carers had been invited to an event held in Brakenhale School on 19 December 2007 to receive information in respect of relevant legal matters. BFVA worked with the Citizens' Advice Bureau to obtain information relating to benefits and eligibility. There were occasional articles in Town and Country and the quarterly BFVA newsletter included two pages concerning carers, one for young carers and the other for adult carers. There were 600 entries on the newsletter mailing list and it was hoped that it was seen by others as copies were displayed in community centres, libraries and GP practices.

Information Received from Carers UK (Bracknell Branch)

- 3.33 Barbara Briggs, the Chairman of the Bracknell branch of Carers UK, a national association, gave the Working Group an overview of her role with carers and explained the functions of Carers UK. Mrs Briggs was involved in numerous organisations associated with carers, for many of which Carers UK acted as the umbrella organisation supporting all age groups and disabilities. Her work encompassed Adult Social Care and the health service and included an afternoon tea / conversation group sought by Adult Social Care for consultation purposes, two dementia groups for younger and older sufferers and two stroke groups. Representatives of such groups were members of the Carers UK committee to enhance feedback and networking. Her background prior to undertaking her present role had been that of a carer for 24 hours per day 7 days per week.
- 3.34 There were 45 members of the Bracknell branch of Carers UK and one of its main activities was to organise Carers' Lunches which were open to all carers in Bracknell Forest, over 60 of whom had attended the Carers' Lunch at Christmas 2007. Ex-carers were invited to the Carers' Lunches as they had experience and knowledge to share and were able to assist with consultation / feedback. The Carers' Lunch had been introduced nine years ago as an annual event and popularity had led to it now being held on four occasions per annum. The Lunches also provided Adult Social Care with an opportunity to engage with carers and consult them on needs and services. There were themed and facilitated events featuring speakers on subjects of interest to carers such as

² Source: Carers UK

Adult Social Care provision, health matters, benefit eligibility and legal issues etc. The next Carers' Lunch would include a presentation in respect of the next phase of the carers' grant.

- 3.35 Mrs Briggs confirmed that Bracknell Forest operated differently from other local authorities in that it passed a significant portion of the carers' grant from central Government to BFVA for direct allocation to carers. This arrangement enabled hidden carers to be identified, added to a database of carers and invited to access carers' services and events. Although the national carers' grant to the local authority had increased year on year until two years ago when it had begun to decrease, the Council had increased the amount of funding passed to BFVA and the amounts are set out in paragraph 3.2.
- 3.36 Many carers sought four hour sitting service slots and therefore Carers UK was looking at new funding methods as it was not in a position to provide these in addition to the Carers' Lunches, which were viewed as constituting a break to which carers could bring their cared for if necessary. Many did not see themselves as carers and it was a role that tended to gradually increase as the needs of the cared for grew. Accordingly, Carers UK had asked Adult Social Care to inform carers at the first point of contact of the services available so they knew what was accessible should the need arise. If carers appeared to be approaching crisis point they were encouraged to seek assistance. A link worker with Adult Social Care had identified many hidden carers in the course of her work and advised them to request an assessment whether they felt they required services or not as this enabled accurate data on the number of carers to be compiled. The hidden carers contacted included BME carers. When asked at Carers' Lunches what services and support they required, carers had sought a contact to assist with assessments.
- 3.37 When asked whether Carers UK had a 'wish list', Mrs Briggs advised that the first Carers' Information Pack had been delivered from a wish list. Although carers had also sought a coffee shop where they could meet, interact and leave their cared for whilst they shopped etc., little use had been made of the coffee shop run for carers at the Tea House on Tuesdays for one year. Also, minimal use had been made of the carers overnight respite service provided at the request of Adult Social Care.
- 3.38 Mrs Briggs felt that the carers' grant constituted the greatest change to carers' lives and eased their role. Mrs Briggs had experienced very few problems working with Adult Social Care and she felt that more could be achieved through joint working.

Information Received from Carers at the 'Carers Tea Party'

3.39 In order to gain the views of local carers in respect of the accessibility, range and quality of services available to carers, a group of carers was invited to attend a 'tea party' at Easthampstead Baptist Church to meet the Working Group informally as they preferred this approach to completing a questionnaire. Twelve carers, all of whom belonged to the Carers' Forum, had accepted the invitation. Although this was a small group, they represented the full range of caring. Some carers had more than one caring role and the conditions suffered by their cared for included dementia, Alzheimer's and Parkinson's diseases, osteoarthritis, osteoporosis, learning disabilities, Autistic syndrome and mental health. The discussion focused on the following four questions to carers:-

- a) Is the support you receive to help you provide care appropriate?
- b) How do you get the information you need?
- c) Do you get a break from your caring role and is it what you want?
- d) Is there some other help you would like to see made available?
- 3.40 In the general discussion the point was made that most carers took on the role almost without realising it as the needs of the individual they were looking after developed over time. Much of the caring was seen as part of their normal responsibilities. Their own needs were not taken into consideration until their caring role was considerable and they became aware of their own exhaustion.
- 3.41 Once they were in the system and receiving support for themselves as well as their cared for, carers were complimentary and appreciative of the various respite care and other support available. They were particularly complimentary of the current Adult Social Care and Carers UK provision.
- 3.42 There was considerable discussion on how difficult it was for carers to get information and most admitted they had found it difficult although they appreciated that the situation had improved over the last few years. The main difficulty was that carers were often tied to the home and so information that might be available in libraries, etc., they were unlikely to see. It was felt strongly that information should be easily available through their GP as this was one service they regularly used. It was also suggested that if information could be made available into the home through newsletters, such as Town and Country, this would be very helpful.
- 3.43 There were varied views on carers' own ability to have a break. Some received regular short breaks and others almost no time for themselves. Most used short breaks when their cared for was at a day centre or something similar to catch up on domestic chores. Short breaks of 2 hours at a time were not thought to offer long enough to get involved in any leisure or similar activity.
- 3.44 All of the carers present emphasised that the views they expressed were based on a period over many years as they were long term carers and they did recognise that services had improved considerably over the last few years.
- 3.45 Full details of the responses to these questions are attached at Appendix 1.

Discussion with Councillor Thompson, Pensioners' Champion

- 3.46 Councillor Thompson had received a copy of an early draft report of the Working Group's review and had been invited to meet the Working Group to give his views thereon and to provide information acquired in his role as Pensioners' Champion.
- 3.47 The Working Group was advised that Age Concern provided respite care at its World's End Day Centre where some spaces were purchased by the Council in addition to other day centres. Age Concern also arranged outings for users and a week's holiday in the summer and another, 'Tinsel and Turkey', later in the year to celebrate Christmas. Volunteer carers took part in the outings, which included visits to garden centres and trips on narrow boats, and also in the holidays to give respite care. The charity also offered a handyman service and produced a leaflet which detailed the services available. The Pensioners' Champion advised that a visit to the Day Centre would be beneficial and he confirmed that a number of other agencies provided a service to carers.

3.48 The 'Shopmobility' scheme offered a valuable service for carers.

Visit to Age Concern's Worlds End Day Centre

- 3.49 On the advice of the Pensioners' Champion, the Working Group visited the Worlds End Day Centre, Bracknell, which was leased in perpetuity and run by Age Concern, to meet the Chairman, Barbara Knight, and the Chief Executive, Nina Wilmot, to gain information in respect of the services provided.
- 3.50 Day Centre facilities included a small enclosed garden area, sitting room, dining room, kitchen, bathroom, toilets, activity room, bedroom, an office which was utilised as a quiet sitting room during the afternoon and facilities for toe nail cutting and hairdressing. As it was sixteen years since the Day Centre had opened in June 1992, some of its facilities were in need of refurbishment / replacement and fund raising was taking place with a view to renewing kitchen and bathroom facilities and extending the sitting room area by adding a conservatory.
- 3.51 The Day Centre was open from Monday to Friday and discussions were being held with the Council with a view to obtaining funds to enable Saturday opening also. Many of the Day Centre clients were referred there directly from hospital as part of their care packages. Anyone could refer a client to the Day Centre and some referrals came from the Community Psychiatric Service. Clients visited the Day Centre between one and three days per week depending on capacity. There was constantly a waiting list to access the Day Centre which currently had 55-56 clients in total and could receive a maximum of 20 people per day. It was commented that turnover of clients in the last twelve months had noticeably increased. The Day Centre could accommodate clients for extended periods to offer increased respite care if needed providing that carers collected their cared for. An audit undertaken two years ago had indicated that carers were satisfied with services offered by the Day Centre.
- 3.52 The Day Centre provided various activities such as craftwork and making displays for the activity board and there were proposals to equip the activity room with PCs, a billiard table and facilities for painting etc. 'Recognition' work was also undertaken in the form of quizzes. The Day Centre had a health and wellbeing brief that focused on care of the fail and improving quality of life. The Day Centre organised trips and two holidays each year. Participants were able to bring a carer if needed and, although the charity had insufficient funds to offer carers' holidays, these escorted holidays offered a form of break.
- 3.53 The number of clients with dementia has increased and four to five clients in their 60's with severe dementia attended the Day Centre for respite care as their spouses needed to be in employment. The majority of the remaining clients were in their 80's and in need of much care as they were older and frailer. They tended to utilise the Day Centre for a brief transitional time before entering residential care or because their carers often struggled to cope and the Day Centre offered some respite. Demography of the Borough indicated that there would be a growing number of older people in the future and the Chairman and Chief Executive expressed concern in respect of meeting the associated increase in care needs.

4. Conclusions

From its investigations, the Working Group concludes that.

- 4.1 Carers provide invaluable services to those whom they care for and by doing so they save the taxpayer large sums of money. The Working Group has been very struck with the immense dedication shown by the carers it met, for example in one case the carer had had just one break of one week in a period of five and a half years of caring. Carers deserve to be and are mostly well supported by the Council, whose services have improved significantly over the last few years, according to the carers the Working Group met and the voluntary agency staff it spoke to.
- 4.2 Many carers do not consider themselves to be carers and it is a role that tends to gradually increase as the needs of the cared for grow.
- 4.3 Carers consider that the carers' allowance, which is a maximum of £50.55 per week depending on the receipt of other benefits, is insufficient and they seek opportunities to supplement this through employment. The Working Group recognises that the allowance is set by central and not local government.
- 4.4 Carers seek good day services to enable their cared for to take part in stimulating activities whilst giving themselves respite, shopping / housework and employment opportunities.
- 4.5 The carers' respite grant is considered to constitute the greatest change to carers' lives and eases their role.
- 4.6 Many carers are unaware of methods of accessing services when new to their caring role as they are unable to spend much time away from home and do not receive related information unless it is evident at their GP practice. GPs have a significant role to play in this area as they are often the first point of contact for carers needing support. There is a need for Adult Social Care and GPs to work closely together to improve carers' access to information.
- 4.7 The best method of engaging with GPs may be a system of holding regular meetings with GP practice managers to cascade information to GPs and practice nurses and reception staff. The Carers Strategy Working Group addresses this concern in its Action Plan.
- 4.8 As there is competition for article / promotional space in the Council's 'Town and Country' magazine, there may be merit in reviewing alternatives such as the inclusion within Town and Country of a separate information 'flyer' leaflet relating to support services for carers which will be delivered directly to their homes.
- 4.9 There is a considerable range of information available for carers. Despite this, the gap between the estimated number of carers in the Borough and those benefiting from support suggests a continuing need to explore new ways of providing information to reach carers.
- 4.10 'Carers Week', an annual event, and the 'Voice of Experience' two-yearly conference provide good opportunities for information exchange.

- 4.11 The five specialist teams in Adult Social Care provide a good service to those in need. This is recognised and valued by the carers whose first priority is to ensure that their loved ones receive appropriate support. This has also been recognised in recent inspections and the Dementia Team winning a national award.
- 4.12 It is also recognised that the support provided by the Bracknell Branch of Carers UK and the Carers Support Team of BFVA is invaluable.
- 4.13 We welcome the Carers Strategy and look forward to the implementation of its Action Plan.
- 4.14 The setting up this year of a new Carers' Information and Support Group is a useful addition to information dissemination.
- 4.15 The work currently being undertaken by the Council and BFVA to improve services for the Indian and Nepali communities is to be welcomed.

5. **Recommendations**

It is recommended to the Executive Member for Adult Services, Health and Housing that:-

- 5.1 The Council investigate a pilot scheme using the 'Look In' to run an advice and information service for carers and the possibility of offering on-site respite care for short periods;
- 5.2 A 'flyer' leaflet providing information and contact details relating to services for carers be included in 'Town and County' on a regular basis to access hard to reach carers;
- 5.3 Staff in Adult Social Care be asked to work in partnership with the Berkshire East Primary Care Trust and general practitioners to implement an effective system of drawing to the attention of carers up to date information relating to services for carers (as is planned in the Carers Strategy Action Plan);
- 5.4 Staff in Adult Social Care be requested to work with health centres and hospitals to ensure that they provide appropriate information to carers;
- 5.5 The Chief Officer: Adult Social Care be asked to support partners in the delivery of the Carers Strategy Action Plan; and
- 5.6 Performance against Local Area Agreement targets for National Indicator 135 (Carers receiving needs assessment or review and a specific carer's service, or advice and information) be reported on regularly to the Social Care and Learning Overview and Scrutiny Panel.

It is recommended to the Social Care and Learning Overview and Scrutiny Panel that:-

5.7 The Social Care and Learning Overview and Scrutiny Panel may wish to give future consideration to reviewing services to support young carers and parents of children with learning disabilities.

6. Glossary

BFVA	Bracknell Forest Voluntary Action
BME	Black and Minority Ethnic communities
BWC	Bracknell and Wokingham College
CAMHS	Child and Adolescent Mental Health Services
CSCI	Commission for Social Care Inspection
GP	General Practitioner
JSNA	Joint Strategic Needs Assessment
LD	Learning Disabilities
O&S	Overview and Scrutiny
PCT	Berkshire East Primary Care Trust
SCL	Social Care and Learning
The Council	Bracknell Forest Council

Detailed Responses to the Questions to Carers

- a) <u>Is the support you receive to help you provide care appropriate?</u>
- i. One carer had experienced difficulties in obtaining a carer's assessment for which there had been a lengthy wait owing to the number of carers in need of assessment. She found that as her needs were changing continual reassessment was required. Although she had initially remained independent and not sought help, a new GP referred her cared for to a Falls Clinic via Adult Social Care at which point she had accessed Intermediary Care services. She praised the service pattern that had then emerged and commented that her previous GP would not have offered such assistance.
- ii. A second carer, whose cared for suffered from memory loss, had also encountered difficulties and delays in accessing services. One year ago, when suffering from exhaustion, depression and stress, the carer herself was referred to Adult Social Care by her GP as she could no longer cope without assistance. Long waits for incontinence pads and day centre placements were then experienced. The carer knew of other carers who had experienced lengthy waits for services.
- iii. Although assistance with completing assessment forms was available, there was said to be a two-three month wait for this and several carers claimed not to have ever received a form. Delay in the GP referral process was generally highlighted as an issue which Adult Social Care was endeavouring to resolve. It was recommended that where GPs were unhelpful an alternative doctor be sought. One carer cited an example of not being allocated a social worker which had been recommended by her GP.
- iv. Another carer had been unaware of the process of accessing services and knowing who to contact and felt that carers should be made fully aware of this at the outset. Although GPs were usually the first point of contact, she had a different GP to her cared for and the links had not been made. She found the assessment forms complicated to use.
- v. One carer reported that his GP had advised him to approach Adult Social Care for assistance with caring as a result of which he had been allocated a care manager who provided information and advice. He was satisfied with the services provided and felt that this was the correct route for accessing services.
- vi. The carers' assessor in Adult Social Care was held in high regard and was said to find half of those she assessed in need of services which led to her frustration at the lack of resources available to support them. A carer made the point that carers focused on their cared for which diminished their time and energy for seeking services for themselves. As the nature of the caring role caused carers to face greater challenges and stresses on some days than others, there was a danger of their needs being under assessed when assessments were undertaken on less demanding days when their needs were less visible. Also, carers could lack specific awareness of all the caring functions they undertook as these were carried out automatically as part of the daily routine.

- vii. Another carer described the difficulties she had encountered with attempting to access services to assist with caring for her son who suffered from mental health conditions. Approaches to senior staff in Adult Social Care and the local MP had been required in order to receive assurances that the Department would assist. Despite these assurances, being given contact names and informed that she had a right to a carers' assessment, she continued to wait for meetings and assessments.
- viii. The carers appreciated the support and advice offered by Carers UK which enabled them to access information from many different professionals and obtain solutions to problems. It was felt that support for carers had improved over the last year or two and this included the annual grants for carers' breaks. Another recent development was the domestic support service which had been introduced in 2007 by BFVA at the request of the Council to provide a service to frail, elderly and vulnerable people in the community who required assistance with housework, shopping, laundry and pension collecting etc. Help the Aged was reported to act rapidly to help in situations where older people were in need of care and assistance.
- ix. Attention was drawn to three instances where Adult Social Care had advised carers not to install equipment or make adaptations to their homes, such as the installation of a disabled bathroom, to accommodate their cared for as they may be eligible for a grant from the Council which was repayable with interest. Some carers were reported to have waited for up to one to two years for assessment of eligibility for such grants which caused them difficulties.
 - b) How do you get the information you need?
- The carers generally felt that information concerning services for carers should Χ. be made more readily available, particularly for new carers who would benefit from learning from experienced carers. The Working Group was mindful that new carers initially felt able to cope unassisted but their needs grew in time. GP practices, hospitals, chemist shops, supermarkets, shopping centres, libraries, day centres, notice boards and the British Legion were suggested as suitable places to promote such services. As much of carers' time was spent at home with their cared for, it was felt that information should be delivered directly into the home. The Borough's 'Town and Country' publication was identified as a means to achieve this but, as it was said to contain insufficient article space, it was suggested that it be expanded to include information relating to carers' services. One carer made reference to a mental health carers' awareness day that had been held elsewhere and another drew attention to an event being held at Brakenhale School to advise on disabilities, work and pensions. It was felt that Adult Social Care was not aware of all of the opportunities for carers provided and funded by BFVA.

c) Do you get a break from your caring role and is it what you want?

xi. The carers were in receipt of respite care in order to attend this meeting. It was reported that in instances of mental health it was not known whether the cared for could be left until the last minute owing to the possibility of sudden mood changes or other manifestations which prevented their carers from booking activities in advance. Some carers needed to be in very frequent telephone contact with their cared for which lessened the benefit they gained from respite care. Carers generally sought more and longer breaks which left them

refreshed and better equipped to care. The amount of breaks received varied considerably and whilst one carer received a break on one evening per month, another benefited from respite care on three occasions per month. A third carer advised that she had received a break of one week in the last five and a half years and was attempting to secure a placement for her cared for at a day centre to increase her opportunities for receiving breaks. One cared for attended skills for life and continuing education courses at Thames Valley University which gave him personality and self-confidence development opportunities whilst his carer received a break. Attendance at The Ravenswood Centre, the Ark charitable trust and leisure centres offered the double advantage of benefiting both the cared for and carer. A carer expressed the view that the demise of traditional day services was detrimental to both carers and cared for as such services enabled carers to pursue employment whilst their cared for took part in stimulating activities. The modern service alternative of cared for spending in the region of two hours per session at a leisure centre or similar activity was not thought to offer these opportunities.

- d) Is there some other help you would like to see made available?
- xii. A carer reiterated the view that good day services to assist carers and benefit cared for were sought. The carers' allowance was considered insufficient and prospects to supplement this through employment were needed. Another carer supported this view feeling that carers were denied their own wishes which came second to their cared for and she saw day services as her only chance to regain time and life opportunities for herself. She struggled to maintain a house and garden whilst looking after her cared for and emphasised the point that carers should be enabled to pursue employment opportunities bearing in mind that financial resources were made available to provide residential care for those without carers. A carer drew attention to Woodlands Assessment Centre where he took his cared for one day per week to enable him to undertake domestic chores or pursue other activities. Carers were made aware of other day and respite care centres in the area.
- xiii. Carers expressed a lack of peace of mind for the future. They drew the Working Group's attention to the numerous amount of cared for off-spring in 'supported living' who were of 40 years of age or more and raised concerns with regard to who would care for them in the future when their parents / carers became aged and frail or died. The absence of staff cover at Glenfield House, a sheltered housing project for clients recovering from mental illness, from 5 to 10 p.m. each day was another cause for concern centred around security issues. Glenfield House was seen as a potentially volatile facility owing to its mixed clientele with mental health conditions of varying types and stages. The necessity to apply for grants each year was taxing for carers, particularly as incorrect use of terminology could prejudice grant eligibility.

<u>CARERS AT THE HEART OF 21ST CENTURY FAMILIES AND COMMUNITIES</u> <u>HM Government – 10th June 2008</u>

1. Definition of a Carer

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

There are approximately 6 million Carers in the UK.

Of those, 3 million Carers are balancing their caring role with employment.

During an average year nationally 2 million Carers begin their caring role and 2 million cease to be Carers.

1 in 10 adults in Britain is currently a Carer, with the majority being females

3 in 5 will become a carer at some point in their life

By 2037, the number of cases is expected to increase to 9 million due to an ageing population

2. Introduction and background

Since 1995 there has been a growing national recognition of the import role Carers have as care providers for our most vulnerable groups of people in our society.

Following the first Act in 1995, Carers (Recognition and Services) Act, which placed a legal duty on Local Authorities to recognise and assess the needs of the carers of clients who where in receipt of services under the Community Care Act 1990, the Prime Minister launched the 1999 National Carers Strategy – "Caring about Carers".

The Government's strategy had three key approaches:

- Information for Carers
- Support for Carers
- Care for Carers

To support the strategy the Government introduced the Carers' Grant, funding to Local Authorities to develop respite opportunities, support services and comprehensive information for all ages of Carers, including Young Carers.

Following the first strategy there has been the introduction of significant legislative changes to continue to raise awareness, impact on the role of Carers through assessment, increase recognition and the development of service provision:

• The Carers & Disabled Children Act 2000

- The Carers (Equal Opportunities) Act 2004
- **The Work & Families Act 2006** (extended the right to request flexible working to employees)

3. "Our Health, Our Care, Our Say" 2006

In 2006 the Government's White paper "Our Health, our care, our say" announced a new deal for Carers made up of four parts:

- a) A comprehensive national information service. To be in place Spring 2009. £2.775m per year available.
- b) The establishment of Caring with Confidence, a training programme for carers. Training to be available August 2008 & on a distance-learning basis from December 2008. £46m per year.
- c) Emergency Care Cover. £25m additional funding per year from October 2007.
- d) A revised Prime Minister strategy for Carers, a ten-year strategy supported by a set of commitments.

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

In June 2008 the Government launched a new 10 year strategy for Carers.

Commitments

The 2008 Strategy sets out a strategic agenda for the next 10 years to improve the lives of those who care for the ill, frail or disabled relatives or friends.

Short term: Commitments

- Increased funding for breaks for carers.
- Pilots to assess innovative approaches to the provision of breaks, their quality and their cost-effectiveness.
- o Sharing of best practice in supporting carers across local authorities.

Longer term: Identified priorities

- Consideration of further increases in break position, taking account of evidence about quality and outcomes.
- Dissemination of models of best practice on quality and innovative approaches to break provision, based on evidence gathered in the pilots.
- In the context of community empowerment and the reform of the care and support system, to consider how the relationship between local authorities and the third sector and carer-led organisations can be developed to make better use of the expertise of these organisations, and to provide carers with greater choice and

control over the way in which services are provided to them. As part of this, we will also examine how best to utilise the Carers Grant to the benefit of carers.

Funding

By March 2011, £1.7 billion for councils to support Carers through the Annual Carers Grant.

Within the £1.7 billion, £25m a year is for emergency break provisions.

A further £22m committed to set up an information service via a helpline, plus a training programme for Carers.

Also, £3.4m to directly support Young Carers through extended Families Pathfinders.

Currently £255m invested on new commitments as part of the Strategy.

The Vision

By 2018, Carers will be universally recognised and valued.

Carers support will be tailored to meet individual needs, enabling Carers to maintain a balance between their caring responsibilities, and a life outside of caring, whilst enabling the person they support to be a full and equal citizen.

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

5. Local Demography and Grant Details

Across East Berkshire, based on ONS data of 2001 census there are in the region of **29,966** people over the age of 18 years providing unpaid care on a daily basis.

However, with growing numbers of older people, people with long term conditions and people presenting with specific diseases across the area, we can make an assumption that this figure is an underestimation. This figure does not include Young Carers, who are by the very nature of their situation often hidden.

The total national Carers Grant 2008/09 is £224m;

East Berkshire Grant allocations to Local Authorities for 2008/09 are:

 Bracknell Forest
 £ 327,000

 RBWM
 £ 420,000

 Slough
 £ 514,000

Bracknell Forest

The 2001 census identified 8,278 Carers in the following categories:

- 6,230 Carers provide 1 19 hours care per week (per person)
- 676 Carers provide 20 49 hours care per week (per person)
- **1,372** Carers provide 50 or more hours care per week (per person)

In 2007, 522 Carers were known to Adult Services.

In 2007/08 **510** Carers received an assessment of their needs. During 2007/08 **510** Carers received services to support them in their caring role. During 2007/08 **31** Young Carers received services providing support and respite.

Key areas of spend were:

Adult Carers Development Worker Flexible breaks for carers including: Holidays, Accessing learning events and training Driving lesions Group activities/outings Carers' lunch Respite breaks

Royal Borough of Windsor & Maidenhead

The 2001 census identified **11,501** carers in the following categories:

- **8,889** Carers provide 1 19 hours care per week (per person)
- 915 Carers provide 20 49 hours care per week (per person)
- **1,697** Carers provide 50 or more hours care per week (per person)

In 2007, 1421 Carers were known to Adult Services.

During 2007, **330** Adult Carers were receiving services in support or their caring. During 2006/07, **279** Carers had received an individual assessment or review of need, with a further **1083** having had their needs assessed or reviewed jointly.

RBWM Carers Grant 2008/09 £ 420,000

Key areas of spend being:

Children – Children with Autism respite; Children with Disabilities respite; Spot Purchase includes Holiday Projects.

Older People – EMH respite; Voucher system; Alzheimer society.

Learning Disability – Spot Purchase; Respite.

Mental Health – Spot Purchase; Emergency Support.

Misc: - Young Carers Project; Princess Royal Trust for Carers; Hospice Asian Worker.

<u>Slough</u>

The 2001 census identified **10,187** carers in the following categories:

- **6,924** Carers provide 1 19 hours care per week (per person)
- **1,267** Carers provide 20 49 hours care per week (per person)
- **1,996** Carers provide 50 or more hours care per week (per person)

In 2007/08 1,853 Carers were known to Adult Services.

In 2007/08 **629** Carers received an assessment of their needs. During 2007/08 **629** Carers received services to support them in their caring role. During 2007/08 **249** Young Carers received services providing support and respite.

Key areas of spend were:

Carers Support Service – Specialist workers Generic and Mental Health Support Workers BME Carers Link Workers for parents of adults with LD Carers Respite including specific care group respite - EMI, Mental Health, BME, PDSN and LD Young Carers Worker Young Carers Respite and time off activities Summer and school holiday "Respite Scheme for parents of disabled children" Carers Training, including specific Mental Health Training Carers Taxi Voucher Scheme Carers Assistance Voucher Scheme Carers Direct Payments Specialised Dementia Carers Respite Carers Support Group x 5 Carers Forum Carers Emergency Responder Service

6. Next Steps – Implementation

The Government is committed to implement the vision set out in the 2008 Strategy and has established a Standing Committee on Carers (December 2007) who will have a key role in advising the Government of the progress of the strategy. This will include a specific overview on equalities issues and advising on ways Carers can be further supported as demography changes.

The Government also plan to establish a programme board to complement the work of the Committee. The board will be responsible for ensuring preparatory work is undertaken to support the delivery of the longer-term proposals set out in the Strategy and that the next two years' commitments are implemented.

The JSNA and LAA will maintain a regional and local overview of progress which will be monitored by the Local Performance framework. However, the Government has made a series of new commitments within the document, which are laid down as follows:

Short term: Commitments:

• Establishment of cross-government programme board

- Module on Carers in an Omnibus Survey
- Inclusion of a question on Carers in the 2011 Census
- A national Carers' experience survey

Longer terms: Identified priorities

 Review of National Indicator Set to set ensure that Carers' experience of service is measured

Recommendations for BE JSCB

One of the most significant announcements in the Strategy is the increased funding available for respite breaks. There will be an additional **£150m** which will be allocated to PCTs. This funding will require PCT's to work with LA's to develop and publish joint plans for the provision of breaks.

The following points are recommended to the board for discussion and as potential actions for board agreement:

- Map existing respite services across Berkshire East including detailed spend
- Identify gaps
- Agree resources
- Identify potential jointly commissioned respite opportunities for Carers from all care groups including Young Carers
- Develop services that can be commissioned via PBC's
- Agree monitoring and reviewing processes