

Carers Strategy – draft outline

Contents

- 1. Foreword**
 - 1.1 *Definitions***
 - 1.2 *Vision***
 - 1.3 *Strategic Vision for Brighton & Hove***
 - 1.4 *Personalisation***
- 2. The National Picture**
 - 2.1 *Facts and Figures***
 - 2.2 *Finances and Employment***
 - 2.3 *Legislation***
- 3. Assessment of need**
 - 3.1 *Carers of adults in Brighton and Hove***
 - 3.2 *Carers of disabled children in Brighton and Hove***
 - 3.3 *Who are the carers caring for?***
 - 3.4 *Equalities and Inclusion***
 - 3.5 *Current Funding streams for carers of adults***
 - 3.6 *Current funding streams for parent carers***
- 4. Key Principles, Priorities and Commissioning Implications**
 - 4.1 *Integrated & personalised services***
 - 4.2 *A life of their own***
 - 4.3 *Income & employment***
 - 4.4 *Health & well-being***
 - 4.5 *Young carers***

5. Implementation

1. Foreword

1.1 Definitions:

- 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.
- Parent carers are people with parental responsibilities (parents, grandparents, foster parents, adoptee parents and others) who also provide additional care, assistance and support to children with learning or physical disabilities, complex health needs or illness, or emotional behavioural difficulties.
- Young carers are children and young people under 18 who provide, or intend to provide, care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility, which would usually be associated with an adult.
- Sibling carers are children and young people who contribute to the care of their siblings who have additional needs.

1.2 Vision

The National Strategy for carers says that 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 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.*

1.3 Strategic Vision for B&H:

The Carers' Development and Commissioning Strategy 2009 - 2012 will set out the vision for the future development and commissioning of services to support carers in Brighton and Hove for the next three years. It is a joint strategy across Brighton & Hove City Council and NHS Brighton and Hove.

The Strategy recognises the importance of carers as expert care partners in supporting those with care needs to live independently in the

community and aims to reduce the social and health inequalities faced by carers and those they care for.

1.4 Personalisation

Ensuring that carers are an integral part of the Adult Social Care vision for Personalisation will go a long way to meeting the key priorities in the national strategy and the local priorities for carers in Brighton and Hove:

“Our vision is to create an integrated range of effective services and opportunities that deliver timely and appropriate responses to individuals’ needs and aspirations and support them in leading fulfilled and healthy lives .Our commitment is to empower people to make informed choices about the sort of support that suits them and to achieve the outcomes they want to maximise their independence and quality of life. This includes safeguarding those people whose independence and well being are at risk of abuse and neglect.”

To deliver this vision, we will re-design our service to offer:

- clear advice and information through multi-skilled contact point(s);
- self-assessment and easy access to simple services (e.g. equipment, community services, Telecare);
- identification of, and signposting to, partnership solutions to improved quality of life;
- self-directed support options at all stages for all social care users;
- an integrated approach to re-enablement for the majority of social care users;
- a robust care management service for those who need it; and
- a professional and effective process to safeguard vulnerable adults.

The new service will work to a set of key principles. It will be a service that:

- enables people to make decisions and choices wherever possible;
- facilitates independence whereby people can access the appropriate resource at the right time and move on;
- is flexible and designed to meet changing needs;
- listens to people’s views and is open to change;
- is fair for all parts of the community and does not discriminate on the basis of income or background; and
- represents good value for money for the community and the person using the service.

2. The National Picture

2.1 Facts and figures

- Every year 301,000 become carers

- The economic value of the contribution that carers make is estimated at £87 billion in the UK. This is equivalent to the cost of the NHS every year.
- 3 in 5 of us will become carers at some point in our lives
- More than 50% of carers in a Carers UK study had sustained a physical injury since becoming a carer and 52% had been treated for a stress related illness
- More than 80% of carers say that caring has damaged their health
- Nearly 21% of carers caring 50+ hours report that they are not in good health, compared with 11% of non-carers
- a third of carers (35%) without good social support suffered ill-health compared to those with good support (15%) – Office of National Statistics
- In 2000, one in six people aged 16 or over (16 per cent) was caring for a sick, disabled or older person and one in five households (21 per cent) contained a carer. These figures represent around 6.8 million adult carers in 5 million households
- Over 1 in 4 (28%) carers spend at least twenty hours per week on their caring responsibilities and 1 in 10 spent 50 hours or more.
- One in five carers (21%) have been caring for someone for at least 10 years and nearly half (45%) have been carers for 5 years or more.
- 10% of GP patients are carers
- 94% of carers manage medication, 23% manage dressings, and 12% give injections
- 175,000 carers are under the age of 18
- 13 million expect to become carers in the next decade
- 18% of carers look after more than one person
- 1.2 million care for more than 50 hours per week

2.2 Finances and Employment

Carers face a number of barriers to employment. These can be individual barriers, for example a lack of skills and confidence due to isolation in the home. Also they may face labour market barriers such as difficulty of accessing jobs that are sufficiently local or accessible to combine with caring roles. Furthermore, employers are not always attuned to carer needs or to provide flexible working arrangements to enable carers to combine work and caring responsibilities. Even after caring has ceased, former carers encounter problems getting re-employed due to gaps in their employment history.

Key facts to understand the multiple vulnerability of families of children with complex needs or disabilities.

- On average, it costs three times the amount to raise a disabled child compared to raising a child with no disabilities¹
- Family breakdown - in the general population of Brighton and Hove, 27% of households with children are single parent households (2001 Census), while single parent households form 36% of families on the Compass database. Single parent household nearly all headed by mums, looking after boys.
- Lower income
 - a) in the population of households with children in Brighton & Hove, 61% of mums and 86% of dads are in paid work, compared to the Compass families where 16% of mums and 63% of dads are in paid work.
 - b) 50% not claiming or unsuccessfully claiming Disability Living Allowance².
 - c) 55% of disabled children live in or on the margin of poverty
- Greater likelihood of disabled children experiencing neglect and abuse.

Of the under 16s on the Compass, 45% live in parts of B&H that rank in the most deprived 20% nationally (i.e. Super Output Areas among the most deprived 20% of all SOAs in the UK.).

2.3 Legislation

Work with carers is underpinned with three specific pieces of legislation:

- Carers (Recognition and Services) Act 1995
- Carers and Disabled Children Act 2000
- Carers (Equal Opportunities) Act 2004

There is also wider legislation such as The Work and Families Act 2006 and case law.

Guidance relating to carers is included in the NHS Constitution handbook and the NHS Operating Framework 2009/10.

The new Section 242 'Duty to Involve' of the NHS Act 2006 provides the guidelines for involving service users in the design, delivery and monitoring of services.

Further details are outlined in Appendix 1.

3. Assessment of Need

3.1 Carers of adults in Brighton & Hove

- 21800 (9%) people identified themselves as carers in the 2001 Census. Of these, 71% care for between 1-19 hours per week, 10% between 20-49 hours per week and 19%, over 4,000 people, for 50 or more hours per week. However, this is likely to be an

¹ Disabled Children & Child Poverty: briefing paper from Every Disabled Child Matters, 2007

² as above

underestimate of the total number of carers across Brighton and Hove. A study for Carers UK (2006) found that 65% of people with a caring responsibility did not identify themselves as a carer in the first year of caring. For a third of them (32%) it took over 5 years before they recognised they were a carer.

- 24% of people aged 50 to 64 are carers.
- Carers Allowance figures provide an additional picture of the number of carers in the area. This is made payable to those who are not in employment or are on a low income providing at least 35 hours of care to a severely disabled person. Across Brighton and Hove there were 1,640 people receiving Carers Allowance in February 2007. This represents an increase of 20% since 2003 highlighting an increase in informal care across the city.
- The economic value of the contribution made by carers is estimated at £222.7 million within the city.
- Around 40% of the working age population providing unpaid care across Brighton and Hove are economically inactive, this figure rises to 70% for those providing care of more than 50 hours per week. People providing care make up 14% of all economically inactive people across the city.

Based on national figures we may expect the following in Brighton and Hove:

- Over 1,000 carers in Brighton and Hove may sustain a physical injury through their caring role and over 1000 may be treated for a stress related illness
- More than 4,500 carers have been caring for at least 10 years and almost 10,000 for five years or more
- Nearly 4,000 carers look after more than one person

3.2 Disabled children in Brighton and Hove

The proportion of children in the UK that are disabled is not known.

Current

estimates range from 5 to 7%. If we consider the conservative estimate of

5% then we would expect there to be just over 2,000 disabled under 16 year olds in Brighton and Hove.

Both nationally and locally, the numbers are increasing of children born with disabilities (for example following IVF treatment and multiple births), those who develop complex needs following injury or illness, and those surviving due to medical intervention not previously possible. NHS Brighton and Hove (in the Joint Assessment of Children's Services (Brighten Up 2008) acknowledges that there is only poor data about the numbers of such children in the city and wide variations in the quality and quantity of services available to their families.

There are just over 1,000 children with additional needs on the Compass Database held by Amaze, representing about 2% of all Brighton and Hove children (aged 0 to 19 years). Therefore if 5 -7% is the expected

proportion of disabled children, the 2006 data represents less a third of those with additional needs. Of those children we do have information about:-

- 72% of the children were male
- 10% of families have more than one child with special needs
- 50% of families where the main or sole carer does not usually get a night's sleep, rising to 60% where more than one child with SEN
- Disabled children more likely to be living in most deprived neighbourhoods
- 24% of parents think their housing is not adequate to meet the needs of their disabled children
- 50% receive no support from extended family, for example from grandparents
- In about a fifth of families with non-disabled siblings, these children share in care of the disabled child
- Only 4% get support from social services (compared to 15% of all families in Brighton and Hove who have any social services support)
- 55% of children on the Compass have been bullied, and 27% have been involved in bullying. Both these figures rise when related to the children who are excluded from schools.
- A child with special needs is seven times more likely to be temporarily excluded from school, and 13 times more likely to be permanently excluded.

3.3 Who are the carers caring for?

We do not know the exact numbers of carers in the city or who they are caring for. However, considering the numbers of people living in the community with disabilities, health or addiction needs, many of whom are supported by carers, gives an indication of caring roles undertaken in the city.

Older People

At the time of the 2001 Census there were a total of 51,058 people aged 60 years and older living in the city. However, in contrast to national and regional trends, the population of older people in the city reduced to 48,100 by 2008 and is expected to decrease further over the next few years. By 2013 the older population is expected to be at its lowest level with 47,600 people aged over 60 living in the city, a 1% reduction from 2008. We then see an expansion in the older population, and from 2013 to 2028 it is expected to increase by 21%, more than 4 times the rate of younger age groups, to 57,600 people.

Disabled People

The Census 2001 reported that 18% of the total population of Brighton & Hove, 44,600 people, reported having a limiting long-term illness. Of these, 21,500 are aged 18-64.

DWP reported in November 2007 that 5% of the population, 12,390 people, were in receipt of Disability Living Allowance. The PCT's Public Health report indicates that by 2010 9.6% (16,179) of adults aged 18-64 in Brighton and Hove will have a moderate to serious disability. The majority of these (77%, 12,458) will have a moderate disability, whereas a significantly smaller proportion (23%, 3,721) will have a serious disability. By 2010 there are predicted to be almost 19,000 adults aged 18-64 with some form of severe or moderate disability. It is likely that many of those with a serious disability

Disabled Children

- It is common for more than one member of a family to have a disability. The Brighton and Hove Compass database has 10% of families with more than one child with special needs and 2% with more than two children with special needs.
- 12% of children on the Compass have a main carer who is disabled themselves.
- Over 1,100 children in the city have statements of Special Educational Needs (SEN). Not all disabled children have a severe enough need to receive a statement e.g. only half the children on the Compass with severe juvenile arthritis have a statement.

HIV/Aids

There are over 1,300 people in Brighton and Hove living with HIV/Aids of whom 85% are gay men and the majority of others are African women. There is a year on year increase of 10% in the numbers of people in the city living with HIV/Aids and the highest increase is amongst African women.

Mental Health

- Brighton and Hove has up to 39% higher incidence of serious mental illness compared with England
- There are variations across the city with the highest indices of need in the eastern parts
- Brighton and Hove has nearly twice the national suicide rate and we are unlikely to meet the 2010 national target for reducing suicides
- There are above 30,000 who would be eligible for CBT or talking therapies support at any one time in the city
- We have over 12,000 people on incapacity benefit, of which 53% are classified as having mental health needs, 7% above the national average
- We have the 2nd highest percentage of alcohol related deaths in men in the country
- We have specific high risk groups in the city including the largest identified LGBT community in the UK
- We have the highest rate of problem drug users in the South East
- B&H spends proportionally more on mental health than another other PCT in the south East and is above the national average

At any one time in the city there are:

- Around 1,500 people receiving support from the recovery team because of a SMI
- 4000 discharged from the recovery team but living with a SMI
- Up to 3000+ carers
- 30,000+ who have a need for CBT because of anxiety or depression
- Between 700 and 1,500 people with schizophrenia
- 400 women with post natal depression
- Around 650 referrals from GP's per month into the single access point for mental health issues

	Number of people in Brighton and Hove aged over 65
With depressive symptoms	Between 3900 and 5900
Experiencing a depressive episode	Between 400 and 2000

Dementia

The expected number of people aged over 65 with some form of dementia in Brighton and Hove should be approximately 3261. Based on national research it is likely that at least 71% of these people have a carer which equates to over 2,300 carers of people with dementia or 10% of all carers in the city.

There are also almost 200 people under 65 with young onset dementia. In new research published in January 2009 in the British Medical Journal half of family carers of people with dementia reported some abusive behaviour towards the person they were caring for and one third report 'significant' levels of abuse.

The paper authors feel that this is unsurprising, as most people with dementia are being cared for by dedicated family or friends, often with little support placing them under enormous strain. The authors recommend giving carers access to respite, psychological support and financial security to help end mistreatment.

A YouGov survey commissioned in 2008 found that 19% of carers sometimes or often feel threatened by the person they care for. Two-thirds said they would like training.

Learning Disabilities

Over 400 adults with learning disabilities live in the community, the majority with, or supported by, family carers. There are 63 young people with learning disabilities who will be 18 in the next 3 years the majority of whom will continue to live at home with family. The national average age for leaving home for all young people is now 24 and it is likely to be that or higher for most people with learning disabilities some of whom will remain in the family home for the long term.

Substance Misuse

There are over 2,500 problematic drug users and over 14,500 harmful drinkers in Brighton and Hove. Supporting carers not only helps carers themselves, but also improves treatment take-up, retention and outcomes for drug users, while bolstering the support they may receive outside of formal treatment.

Cancer

The incidence of cancer in Sussex has remained very stable over the last decade, despite the increase in both population numbers due to further house building, and overall age. Nationally the incidence of cancer is expected to increase by up to a third over the next fifteen years. The impact in Sussex, where we already have such an elderly population, is unknown, but it is encouraging that here is no indication of a rising trend as yet. In 2006 there appeared to be slight increases in cancer deaths in both Brighton and Hastings, although the overall trend continues downwards.

3.4 Equalities and Inclusion

Number of people aged 50 and over providing unpaid care, 2001 Census data

Hours per week caring	All people aged 50 and over	50 to 64	% of carers	65 to 74	% of carers	75 to 84	% of carers	85 and over
1 to 19	7,639	5,215	24%	1,636	16%	685	10%	103
20-49	1,145	690		267		154		34
50 or more	2,598	1,241		667		551		139
Does not provide care	66,060	29,846		16,455		13,534		6,225

- This shows that 17% of the population aged 50 and over provide care compared with 9% of the overall population in the city.

Young Carers

Estimated number and proportion of children (aged 8-17) who are carers in Brighton and Hove, by age and hours caring per week³

	1-19 hours	20-49	50+ hours	Total	Total
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³ Source: Calculated by Prof Saul Becker, University of Nottingham, from Office for National Statistics Census 2001 data.

		hours		number	%
8-11	77	3	6	86	17.5
12-15	215	15	9	239	50
16-17	128	20	8	156	32.5
All	420	38	23	481	100%
All as %	87%	8%	5%	100%	

Disability

In the Census 2001, 13% of carers of adults (?) in Brighton and Hove described themselves as not in good health.

Nationally, 5% of carers are permanently sick or disabled.

BME

The 2001 Census estimated that there were just over 14,200 people from non-white ethnic groups across Brighton and Hove - 5.7% of the city's population. However, the population profile of the city is changing:

- 15% of the city's residents were born outside England – well above national and regional levels
- BME groups were estimated to have increased in size by 35% over the period 2001 to 2004 (against a national increase of 13%)

LGBT Population in Brighton and Hove

The 2001 census did not collect information on sexual identity, but anecdotal evidence indicates that as many as 40,000 people identify as LGBT, or 21% of the total population, in Brighton and Hove. The Count Me in Too survey recommended further research in to the specific needs of LGBT carers and carers of LGBT people in the city.

Religion or belief

The 2001 census showed that over a quarter of the population of the city stated that they had no religion, the second highest percentage of any authority in England and Wales. 59% of the population stated that they were Christian and 1.36% of the population was Jewish. The Muslim population is around 1.4% and the Buddhist population 0.7%.

Financial impact on carers

Caring clearly has an impact on the life chances of carers, on their financial security in later life, and on their employment prospects. For a person in full time work who has to give up their job to care full-time, the current level of Carers Allowance - £48.65 per week - clearly does not provide financial compensation.

The key role played by carers and the £87 billion saving they make to the economy have not been fully recognized.

An Equalities Impact Assessment is attached at Appendix 2.

3.5 Current funding streams for carers of adults

A significant amount of funding for 2009/2010 is committed through ongoing contracts to third sector providers. These contracts will be reviewed during the coming months to consider how they might need to be changed to reflect the priorities in the strategy and address the personalisation agenda. Current expenditure reflects many of the priorities outlined in the strategy although there are areas of service that are not currently funded and will need new resources or a redistribution of existing resources once the key priorities in the strategy have been agreed. From 2010/2011 resource allocation will be more closely aligned to the agreed priorities in this strategy.

Breakdown of funders for carers of adults 2009/10

	£'000s	%
City Council	949	62
NHS Brighton and Hove	436	28
Sussex Partnership Foundation Trust	148	10
Total	1533	100

Breakdown of expenditure for carers of adults 2009/10

	£'000s	%
breaks and services	893	58
information, advice, support & advocacy	328	22
service development & assessments	281	18
Community Engagement	31	2
Total	1533	100

3.6 Current funding streams for parent carers

The Children and Young People's Trust have received Aiming High funding to transform short break services for disabled children. This amounts to £2.2m revenue and £450K capital over three years. The Carers Grant allocation for 2009/10 is approx £203K. The Disabled Children's Strategic Partnership Board meet regularly to discuss the needs of disabled children and their families in the city and inform decisions over expenditure.

4. Key Principles

4.1 Integrated & personalised services

Vision: 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.

Key Priorities from National Strategy

- Key to achieving greater integration of services is the use of more effective holistic assessment which enables the person cared for and their carer to identify their needs, what matters to them and how their own outcomes will best be met. In some circumstances, it will also be important that carers have their own individual assessment, to ensure that specific needs around their own health and well-being are identified.

<ul style="list-style-type: none"> ▪ Training carers to enable them to strengthen them in their caring role and to empower them in their dealings with care professionals as expert care partners.
<ul style="list-style-type: none"> ▪ Training and awareness raising for key professionals from health to housing, to provide better services and support for carers and work with them as expert care partners.
<ul style="list-style-type: none"> ▪ Integrated, partnership working between the NHS, social care services and carers
<ul style="list-style-type: none"> ▪ Actively involving carers in diagnosis, care and discharge planning;
<ul style="list-style-type: none"> ▪ Providing greater support for carers at GP practices and acute trusts;
<ul style="list-style-type: none"> ▪ Personalised, targeted information provided to carers

<p>What have carers in Brighton and Hove said is important to them?</p>
<ul style="list-style-type: none"> • Information and support provided within NHS settings including hospitals, mental health services and GP practices
<ul style="list-style-type: none"> • GPs are essential in encouraging their patients to recognise themselves as carers and signposting them to appropriate support
<ul style="list-style-type: none"> • Confidentiality is a barrier to communication between carers and professionals in mental health services. It needs to be flexible, discussed and negotiated.
<ul style="list-style-type: none"> • Poor communication between professionals can lead to a poor quality of service
<ul style="list-style-type: none"> • Dual diagnosis can lead to people falling between two services and not having their needs met
<ul style="list-style-type: none"> • Mental health service users would benefit from support in daily living skills but this is not always available
<ul style="list-style-type: none"> • Carers don't always want to manage services directly themselves and need choice and control over the delivery of services including the choice not to manage services themselves
<ul style="list-style-type: none"> • Carers need to be involved from the beginning of discussions about Individual • Budgets and any impact on the carer as a result of changes to services needs to be taken into account
<ul style="list-style-type: none"> • Carers need information and advice about how to access services for the cared for person when that person is self-funding
<ul style="list-style-type: none"> • Better information about Carers Needs Assessments
<ul style="list-style-type: none"> • Training for NHS staff in hospitals, primary care and mental health services to increase their awareness of the issues facing carers
<ul style="list-style-type: none"> • Parent carers whose child has a severe learning disability feel that existing third sector providers are limited in what they can offer as this cohort is such a small minority of all parent carers
<ul style="list-style-type: none"> • There is no specific support for parent carers whose child has mental health needs
<ul style="list-style-type: none"> • Good communication between families and professionals is essential at point of diagnosis
<ul style="list-style-type: none"> • Professionals use too much jargon and language that can exclude users and carers
<ul style="list-style-type: none"> • Patients need to have all their needs met when in hospital, e.g. existing medication to be given at right time etc

- Services shouldn't be so dependent on one individual that they are unavailable when that individual is ill/leaves etc

How do we do this already?

- Specialist Carers' Needs Assessments and Reviews provided by the city council and NHS Trusts as well as with third sector providers
- Joint Commissioner for Carers' Services working across Adult Social Care and the PCT
- Joint contracts between Adult Social Care and the PCT with third sector providers for carers' services
- The Federation of Disabled People Direct Payments Advice Service can offer guidance to all carers and users regardless of who is paying for the care
- GP Link Worker – Carers Centre has three years funding to develop services in 15 GP practices with the aim of recognising patients' caring roles, addressing their physical and mental health needs and promoting both third sector and statutory services to further meet carers' needs
- Transition events for young people entering adult services
- Sussex Partnership Foundation Trust has information for carers and staff guidance on managing confidentiality
- Care Passports are used in hospitals and residential care settings. The bright yellow passports take the form of a notebook in which carers can note the special needs of those they care for and can write down questions they wish to ask nurses or consultants. The passport is then kept with the patient and referred to by hospital staff.
- Carers are involved in the selection and training of social work students at the local universities and in delivering carer awareness training in the city council and Sussex Partnership Foundation Trust

Priorities

1. Provide and further develop appropriate, good quality information
 - Information Prescriptions
 - Use of a range of media including websites, factsheets, help lines
 - Map of Medicine is a web based reference guide for NHS staff to ensure best practice in delivering patient care – a local carers' pathway will be developed as part of this
2. Information Sharing Policy Implementation
 - Monitor implementation in SPT and develop practice in other areas including primary care, acute services (Brighton and Sussex University Hospitals Trust), community services (Southdowns Health NHS Trust) and substance misuse services
3. Develop equality of access to services for all carers through targeted information and outreach work across all communities underrepresented in statutory and provider services
 - Ensure needs of BME carers identified and addressed
 - Ensure needs of LGBT carers identified and addressed
 - Ensure needs of carers of people with HIV/Aids identified and addressed

<ul style="list-style-type: none"> • Provider services to work towards promoting their services across all communities in the city and ensuring they are open and accessible to all carers • Ensure needs of parent carers identified and addressed • Take forward good practice from 50+ Project and ongoing work in East Brighton
<p>4. Offer good quality, timely and proportionate outcome focused carers' needs assessments and reviews to meet National Indicator 135</p>
<ul style="list-style-type: none"> • Increase in number of carers receiving a service following assessment/review from xxx to xx in 2009/10 and xxx in 2010/11. • Increase access to carers' needs assessments/reviews through voluntary sector and NHS services and housing • Development of a self-assessment tool for carers will give carers more choice about how their needs are assessed and may offer facilitated assessments with third sector providers • Holistic joint assessments/reviews to complement development of personalised services e.g. Reablement and Individual Budgets • All services responsible for carers assessments/reviews to develop strategies to meet performance targets through the delivery of both high quality assessments/reviews and services to meet the identified needs of carers • Monitor outcomes of assessment/review through city-wide carers' survey and service specific surveys/evaluation tools
<p>5. Self Directed Support options available to carers</p>
<ul style="list-style-type: none"> • 30% of carers of adults access carers' services via Self Directed Support by March 2011 • Carers' needs integral to the development of self directed support for service users • Appropriate support to voluntary sector providers to ensure sustainability of universal services • Appropriate levels of funding available for direct payments to parent carers
<p>6. End of Life Care</p>
<ul style="list-style-type: none"> • Link with End of Life Care strategy for Brighton and Hove to ensure carers' needs are included • Provision of appropriate services to carers supporting cared for at end of life • Access to bereavement support services
<p>7. Carer involvement in the development and provision of services</p>
<ul style="list-style-type: none"> • City-wide carers' survey • Community Engagement Framework - ensure Gateway services are carer aware • Use of Amaze's Compass database • Inclusion of carers on key decision making boards
<p>8. Carers' needs and views taken into account on admission to, discharge from and during stays in hospital as well as in discussion and decisions about diagnosis, ongoing treatments, therapies and services</p>
<ul style="list-style-type: none"> ▪ Care Passports – evaluate uptake and outcomes of current usage ▪ Support to carers at Millview ▪ Support to carers at the Royal Sussex County Hospital ▪ Ongoing support to carers in the community following new diagnosis/hospital

discharge
9. Provision of keyworkers for children and young people with special needs and their carers to ensure services and care are well integrated

Commissioning Implications
<ul style="list-style-type: none"> ▪ Monitor and evaluate the development of the Community Engagement framework and ensure that all Gateway organisations are carer aware and that the needs of BME and LGBT carers and those from other disadvantaged groups are identified consider ways of addressing needs appropriately
<ul style="list-style-type: none"> ▪ Meet National Indicator 135 by providing access to carers needs assessments/reviews through a range of means including development of provision in the voluntary sector, self assessment etc
<ul style="list-style-type: none"> ▪ Ensure carers are represented on decision making boards and panels and they are supported to contribute their knowledge and experience.
<ul style="list-style-type: none"> • Bereavement support
<ul style="list-style-type: none"> ▪ Contracting arrangements to be adapted to reflect move towards Self Directed Support
<ul style="list-style-type: none"> ▪ Survey of carers' needs
<ul style="list-style-type: none"> ▪ Key workers provided to children and young people with special needs and their parent carers
<ul style="list-style-type: none"> ▪ All services responsible for carers assessments/reviews to develop strategies to meet performance targets

4.2 A life of their own

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

Key Priorities from National Strategy
<ul style="list-style-type: none"> ▪ Carers should have the opportunities and space they need to participate in activities outside their caring role. They should be free to have an identity that is separate from that of the people they support. Carers have the right to expect these freedoms, which others take for granted, and to avoid the social exclusion that may result from having no life outside caring.
<ul style="list-style-type: none"> ▪ Greater emphasis on the provision of planned breaks, which will provide carers with the time to take up the same work, education, leisure and training opportunities as anyone else.

What have carers in Brighton and Hove said is important to them ?
<ul style="list-style-type: none"> • Parent carers would like funding for breaks for the whole family
<ul style="list-style-type: none"> • Carers benefit greatly from the opportunity to go on holiday, some with, others without, the cared for person
<ul style="list-style-type: none"> • Eligibility criteria for learning disability services means that some cared for people are receiving few or no services but carers are still undertaking regular and substantial caring roles

<ul style="list-style-type: none"> • Day services for people with dementia following diagnosis
<ul style="list-style-type: none"> • Assistance with transport to and from hospital
<ul style="list-style-type: none"> • Peer support
<ul style="list-style-type: none"> • Media representation of poor quality services can discourage users and put additional pressure on carers
<ul style="list-style-type: none"> • Some users and carers are reluctant to pay for services putting additional pressure on carers
<ul style="list-style-type: none"> • Care at home can be more appropriate for people with dementia but there is limited availability
<ul style="list-style-type: none"> • Support services available within local communities rather than everything being based in city centre
<ul style="list-style-type: none"> • Sustainability of support groups professional input withdrawn

<p>How do we do this already?</p>
<ul style="list-style-type: none"> ▪ Relief care in the home provided by third sector and independent providers
<ul style="list-style-type: none"> ▪ Day service for people under 65 with young onset dementia
<ul style="list-style-type: none"> ▪ Monthly Saturday day service for adults with learning disabilities specifically for carer relief
<ul style="list-style-type: none"> ▪ A wide range of generic, care group specific and neighbourhood based support groups for carers and former carers
<ul style="list-style-type: none"> ▪ Spot Purchase Budget - ring-fenced budget allocated to carers on an individual basis to meet identified need for a break or service following assessment or review.
<ul style="list-style-type: none"> ▪ Emergency Back Up Scheme

<p>Priorities</p>
<p>1. To extend the choice and accessibility of quality break opportunities for carers</p>
<ul style="list-style-type: none"> • Support a range of voluntary and independent organisations to provide flexible breaks for carers • Use of self directed support to develop flexible breaks and services for carers • Explore need for home-based relief care for carers of people with functional mental health needs • Development of services to meet the needs of people under 65 with dementia including those whose condition has developed beyond early to moderate dementia and whose needs can not be met by the current day service provision. • Development of short breaks for children and young people with special needs to provide respite to parent carers • Accessible leisure opportunities for children and young people with special needs and their parent carers • Funding available for parent carers to increase choice and control through use of Direct Payments
<p>2. Provision of carers' services that support carers in their caring role</p>
<ul style="list-style-type: none"> • Through development of Self Directed Support • Explore use of Telecare in supporting carers
<p>3. Support to carers wishing to access leisure activities</p>

<ul style="list-style-type: none"> ▪ Extend benefits of Compass card for parent carers and their children ▪ Appropriate transport is key to enabling carers and cared for to access leisure facilities
4. Support to carers to plan for the future
<ul style="list-style-type: none"> • Legal advice re discretionary wills and trusts • Emergency Back Up Scheme

Commissioning Implications
<ul style="list-style-type: none"> ▪ Consider equity of access to breaks services in relation to referral routes and charging policies
<ul style="list-style-type: none"> ▪ Consider the quality and cost-effectiveness of break provision
<ul style="list-style-type: none"> ▪ Increase capacity of relief care in the home to meet demand pressures through combination of current providers and Individual Budgets
<ul style="list-style-type: none"> ▪ Explore need for home-based relief care for carers of people with functional mental health needs through piloting of service
<ul style="list-style-type: none"> ▪ Use of Carers Grant and Aiming High monies to meet identified needs of parent carers for breaks and leisure opportunities with their children including through the use of direct payments with appropriate support

4.3 Income & employment

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

Key Priorities from National Strategy
<ul style="list-style-type: none"> ▪ To ensure that carers have the opportunity to combine paid employment with their caring role through the provision of better services, increased break provision, easier access to training and skills and more flexible working opportunities
<ul style="list-style-type: none"> ▪ Access to good benefits advice
<ul style="list-style-type: none"> ▪ Jobcentre Plus improving the way they work with carers and can provide support to carers in returning to work
<ul style="list-style-type: none"> ▪ Awareness-raising with employers around the right to request flexible working and supporting carers

What have carers in Brighton and Hove said is important to them?
<ul style="list-style-type: none"> • Concern about employer's perception if they request flexible working • Caring responsibilities leading to poor health can be reflected in sickness records and impact on employment opportunities

How do we do this already?
<ul style="list-style-type: none"> • MACS Money Advice and Casework Service has Big Lottery reaching communities funding to provide assistance with financial issues including bank

accounts; debts - helping with financial statements and negotiating with creditors; benefits - carrying out benefit checks and applications; dealing with utility suppliers.
<ul style="list-style-type: none"> • Free legal advice surgeries at the Carers' Centre
<ul style="list-style-type: none"> • Adult Advancement and Careers Service is a pilot project that will offer information to residents and workers and direct delivery co-located advice services in three areas of the city

Priorities
1. To work with partners and local employers to help carers take up and/or remain in employment.
<ul style="list-style-type: none"> ▪ Develop a carers' policy template and promote with for local employers ▪ Provide training (using the DVD) to local employers to increase understanding about the role of caring and their needs as employees. ▪ Working carers who have had an individual carers assessment will be encouraged to share this assessment with their line manager as a first step in exploring how caring responsibilities impact on work patterns, and thereby providing an opportunity to begin a meaningful dialogue on what might be done to assist both the employee and the employer.
2. Access to benefits and money advice
3. Partnership working with JobCentre Plus
<ul style="list-style-type: none"> • Care Partnership Manager will be appointed April 2009 to the local Jobcentre Plus and we will explore ways to engage and work with them to consider employment opportunities for carers
4. Access to education and training.
<ul style="list-style-type: none"> ▪ Provision of alternate care to enable carers to take up education and training ▪ Develop links with the Learning and Skills Council and local universities to provide discounted/free access to courses for carers. ▪ Explore opportunities for working with Connexions (targeting young carers in supporting all 13 – 19 years old on learning, training and work)

Commissioning Implications
<ul style="list-style-type: none"> ▪ To support parent carers to make successful applications for DLA for their children

4.4. Health & well-being

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

Key Priorities from National Strategy
<ul style="list-style-type: none"> ▪ Every carer should be supported so that caring does not adversely affect their health. ▪ Services and support to carers should enable them to stay mentally and

physically well throughout their caring role
<ul style="list-style-type: none"> ▪ Short-term, home-based respite established for carers in crisis or emergency situations
<ul style="list-style-type: none"> ▪ The needs of carers should be built into the care planning process for people with long-term conditions
<ul style="list-style-type: none"> ▪ Psychological distress is experienced by many carers and needs to be recognised at an early stage
<ul style="list-style-type: none"> ▪ PCTs should aim to create a more personalised service that provides support for carers by recognising their need for breaks from caring.
<ul style="list-style-type: none"> ▪ Involvement of carers in all care planning from diagnosis to discharge and beyond
<ul style="list-style-type: none"> ▪ Take into account the health of the carer to ensure continuity of care for the person being cared for
<ul style="list-style-type: none"> ▪ Access to information relevant to the care and needs of the person being cared for

What have carers in Brighton and Hove said is important to them ?
<ul style="list-style-type: none"> • Carers worry about how they would manage in a crisis
<ul style="list-style-type: none"> • Carers, particularly those caring for an adult son/daughter, would like plans to be put in place for the future with input from key professionals to address both care and financial issues
<ul style="list-style-type: none"> • Health checks for carers
<ul style="list-style-type: none"> • Flexible booking arrangements at GP surgeries for carers

How do we do this already?
<ul style="list-style-type: none"> ▪ Good quality information, advice, support and advocacy provided by the third sector offered both as generic service and targeted at specific care groups
<ul style="list-style-type: none"> ▪ Back Care Service providing advice in safe moving and handling and the loan of equipment to all carers
<ul style="list-style-type: none"> ▪ Looking After Me course for carers
<ul style="list-style-type: none"> ▪ Free counselling from Relate for carers
<ul style="list-style-type: none"> • Access to low cost voluntary sector counselling, e.g. Federation of Disabled People, Age Concern,

Priorities
1. Access to support in NHS services
<ul style="list-style-type: none"> • Development of GP Link Worker scheme • Ensure PALS information service includes information relevant to carers • Develop a network of Carers' Advisers based across a range of NHS settings to include acute and community services and provide continuity of support to carers in their own homes following diagnosis/treatment/in-patient care. • Parent Carer Plus: a flexible specialist key worker approach built around informing, supporting and involving parent carers during and after the discharge process from RACH • GP Practices – Carers Advisers working within GP practices to offer a regular presence, advice to practice staff and direct support to carers

2. Access to advice and training
<ul style="list-style-type: none"> • Continue back care service for carers • “Looking After Me” courses • Pilot Mindfulness Based Cognitive Therapy course through Brighton Buddhist Centre • Dementia training for carers • Health care training, e.g. medications, wound management etc
3. Access to emotional support
<ul style="list-style-type: none"> • Provision of information, advice, support and advocacy • Provision of Insider Guide and Triple P courses to parent carers and development of Resilience Therapy techniques • Increased access to psychological therapies – monitor uptake of IAPT by carers and outcomes • Develop transition services to support carers following bereavement/end of caring role and for parent carers during child’s transition to adulthood with a focus on work/education/training and reduction in isolation

Commissioning Implications
<ul style="list-style-type: none"> ▪ Pilot service in RSCH 2009/10
<ul style="list-style-type: none"> ▪ Continuation of back care service
<ul style="list-style-type: none"> ▪ Continue to fund and develop information, advice, support and advocacy
<ul style="list-style-type: none"> ▪ Provide Resilience Therapy training for carers
<ul style="list-style-type: none"> ▪ Develop transition services to support carers following bereavement/end of caring role and for parent carers during child's transition to adulthood with a focus on work/education/training and reduction in isolation

Young carers

Vision: 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.

Key Priorities from National Strategy
<ul style="list-style-type: none"> ▪ Protecting young people from inappropriate caring
<ul style="list-style-type: none"> ▪ High quality targeted support is accessible to young carers who need it
<ul style="list-style-type: none"> ▪ Better joined-up, whole-family support to families affected by illness, disability or substance misuse who have young carers
<ul style="list-style-type: none"> ▪ Universal services – schools, GPs, hospitals – have a vital role in providing support, understanding and practical guidance to young carers

What have young carers in Brighton & Hove said is important to them ?

young carers top ten wishes...

The most helpful groups are ones where you can talk about difficult feelings with young people in a similar situation

Carers project worker to support us to engage in new activities and attend activities provided by the Young Carers Project would most help with the difficulties of getting out to do activities and meeting new friends

We don't want to have to do personal care

8-10 year olds

Someone to support us to go out as a family

Paid domestic help would most reduce the impact of our caring role in the home

16-25 year olds

1:1 confidential support so that we feel informed about our choices and options

People in authority should let us know they are working for us and speaking up for us

We enjoy cooking to help at home

In an emergency we would like to have a pre-prepared plan of action (made with young person and family) to follow; kept by the school, Young Carers Project etc containing names and phone numbers of people to contact

The best way to raise awareness in schools is in PSHE lessons and sessions for pupils and teachers to understand some of the difficulties faced by young carers

How do we do this already?
<ul style="list-style-type: none"> ▪ Casework and assessments for 8-17 year old young carers
<ul style="list-style-type: none"> ▪ Transitions project for 16-25 year olds
<ul style="list-style-type: none"> ▪ Activities and group work
<ul style="list-style-type: none"> ▪ Targeted support for young carers of substance misusers

Priorities
1. Identification and recognition of young carers at point of assessment of cared for person
<ul style="list-style-type: none"> ▪ Appropriate services to cared for person to minimise impact on child(ren) ▪ Support for parents to be parents and family to be a family
2. Joint working between services for adults and services for children
<ul style="list-style-type: none"> • Joint protocol between adult services and CYPT • Jointly commission young carers assessment services • Family Pathfinder • Transitions Project
3. Ensure needs of young carers of substance misusing parents identified and addressed
<ul style="list-style-type: none"> ▪ Assessment services ▪ support services
4. Support for young carers in schools
<ul style="list-style-type: none"> • awareness raising in schools with teachers & other staff • awareness raising in schools with pupils • support in schools
5. NHS Services
<ul style="list-style-type: none"> • Ensure that the development of Carers' Advisers in NHS settings includes recognition of and support for young carers

6 . Emergency Back-Up scheme
<ul style="list-style-type: none"> ▪ Expand existing scheme to meet needs of young carers

Commissioning Implications
<ul style="list-style-type: none"> ▪ Jointly commission young carers assessment services with CYPT, consider future of this service from April 2010
<ul style="list-style-type: none"> ▪ Assessment and support needs of young carers of substance misusing parents
<ul style="list-style-type: none"> • Work in schools to raise awareness with both pupils and staff, contribute to PSHE (personal, social and health education) curriculum, develop guidance for schools, deliver casework to individual young carers and support transition between primary and secondary schools.
<ul style="list-style-type: none"> • Work in colleges and universities to raise awareness, deliver casework , develop links with student support services, embed young carer training into health and social science syllabi.
<ul style="list-style-type: none"> • Availability of funding for respite breaks, activities and support groups for young carers

Appendix 1.

Legislation

Carers (Recognition and Services) Act 1995

Where a carer is providing, or intends to provide, substantial care on a regular basis, they are entitled, on request, to an assessment when a local authority carries out an assessment of the person cared for in respect of community care services or services for children.

The results of the carer's assessment should be taken into account when the local authority is making decisions about services to be provided to the user.

Carers and Disabled Children Act 2000

Carers (aged 16 or over) of an Adult

- Right to a Carers Assessment (even if the person they care for refuses Social Services assessment or contact)
- Councils now have the power to provide services to carers
- Councils have the power to charge carers for services
- Direct Payments Schemes for carers
- Voucher schemes so person cared for can purchase services which allow the carers to get a break

People with Parental Responsibility for a Disabled Child

- Right to an assessment
- Direct Payments
- Short term break Voucher Schemes

Carers (Equal Opportunities) Act 2004

Clause 1 Duty to inform carers of their right to an assessment

This introduces new provisions to the 1995 and the 2000 Acts giving local authorities a duty to inform carers that they may have a right to an assessment.

Clause 2 Assessment of Carers

This builds on assessments undertaken through the above Acts so that councils have a duty to consider the wishes of carers concerning employment, training, education or leisure activities and take these into account when providing services.

Clause 3 Co-operation between Authorities

NHS organisations, local education authorities and local housing authorities must give 'due consideration' to requests by the local authority to become involved in planning services for carers or to provide assistance to individual carers.

The Work & Families Act 2006

The Work & Families Act 2006 came into effect in April 2007 and gives employees who are, or expect to be, caring for another adult, the right to request flexible working. As an employer, Brighton & Hove City Council, along with other major employers in the city, has a responsibility to its own employees who are also carers to ensure that it offers appropriate support and consideration in response to requests for flexible working. In policy terms the City Council and its partners have an opportunity to influence and promote best practice amongst employers in the local economic community.

Coleman Case

In November 2008 the Employment Tribunal in London ruled that protection for carers against discrimination "by association with disability" can be given under existing UK law. This means that employers will now have to ensure that carers in their workforce are not treated differently to other employees, and cannot refuse to employ someone because of their caring role. The Tribunal has ruled that the section defining the meaning of direct discrimination in Disability Discrimination Act 1995 should be read so that it says:

"A person directly discriminates against a disabled person or a person associated with a disabled person if, on the ground of the disabled person's disability, he treats the disabled person or a person associated with the disabled person less favourably than he treats or would treat a person not having that particular disability or association (as the case may be) whose relevant circumstances, including his abilities, are the same as, or not materially different from, those of the disabled person or the person associated with the disabled person" (the words underlined being those that the Tribunal has added).

NHS Constitution

The new NHS Constitution (England) calls for the NHS to recognise the huge value of unpaid care given and gives carers prominence as partners in care.

The handbook accompanying the Constitution talks about the need to treat "family members and carers as experts and care partners" and that support mechanisms to enable carers to develop their skills and confidence are "particularly pertinent where carers participate in providing aspects of care such as rehabilitation exercises, wound or drug management and manual handling."

NHS Operating Framework 2009/10

The NHS Operating Framework says:

"The carers' strategy sets out how we can ensure that we support carers. One key requirement is that PCT's 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 is understood that Strategic Health Authorities will be monitoring PCT performance with this.

