

Report to: **Scrutiny Committee for Adult Social Care**

Date: **27 November 2008**

By: **Director of Adult Social Care**

Title of report: **Provision of short term residential respite care – update report**

Purpose of report: **To update the committee on the position of provision of respite care following the work of the review board which reported to the Committee in June 08.**

RECOMMENDATION – that the Committee considers and comments on the updated position on the provision of bed based respite care since the work of the tabletop review board.

1. Financial Appraisal

1.1 There are no financial implications arising from the recommendation.

2. Supporting Information

2.1 In the spring of 2008 a tabletop review was undertaken to explore the provision of short term residential respite care by Councillors Taylor and Webb. A report to this committee requested an update report in November 2008.

2.2 The conclusions in June were that it was very difficult to establish a clear picture of the level of respite being provided due to inconsistencies in recording information. There was a variation in the distribution of directly provided services (DPS) and independent sector services across the county. The ability to purchase at published prices in areas where the level of provision was low was more difficult.

- There was a shortage of nursing home respite care and development of the four Age Well sites was highlighted by officers as a possible means for increasing provision in the future, subject to agreeing the final service model for these resources.
- The department was confident that, as DPS provision reduced, the increase in demand could be met from the independent sector.
- The Putting People First (PPF) agenda will have an impact on the way in which respite care is provided.
- The Department will seek, where possible, to support people in their own home rather than removing to a residential establishment.

3. Updated Position

3.1 The review board recognised that recent work by ASC, along with central government legislation, will continue to impact on the demand and provision of residential respite care over the next few years. The review board therefore decided that further work by them should be delayed at present. However, given the points highlighted the review board agreed that the Committee should keep a watching brief on respite care.

3.2 | The current position with the provision of residential respite care in both DPS and the independent sector, including a breakdown by working age (<65) and older people (65+) is shown at Appendix 1. This indicates a small upward trend in the use of independent sector provision of respite care for older people.

- ASC has reviewed its residential respite provision and agreed that this will be re-provided where ever possible in the independent sector. To date the Service Placement Team has been able to source all

requests for older people's respite with the independent sector; the majority of these placements are at our published rate and with the Department's Preferred Providers.

- ASC pays a higher rate for respite than for long term placements to reflect the nature of the service and most providers are willing to accept this fee level. Where placements are made with non-Preferred Providers or above our rates it is as a result of specific geographical market conditions or requests from frontline teams for particular homes to be used to meet user need. (From June to September 08 92% of residential respite was at the published rate and 75% of nursing home respite. 88% of residential respite was with Preferred Providers and 82% of nursing respite.)
- ASC currently operates one block contract for respite with the independent sector. This is a single room with Pentlow and Summerdown Nursing Home in Eastbourne. Because ASC pays a higher rate for this room than spot purchased respite and pays for the room regardless of whether it is used, it is important that its use is maximized with void days kept to a minimum. Of note, since the contract began in the summer of 2007, only 9 different service users have used this facility and usage has averaged 90%. Most of these service users are booked in on a rolling basis for a number of periods of respite throughout the year.
- The Putting People First Programme is being established including a project to develop Self Assessment Tools, a Resource Allocation System and Personal Budgets. This work is in early stage development and will be reported at regular intervals to the Scrutiny Committee. It is unlikely to impact on respite care in the next 6 – 12 months.
- The services to be developed at the four Age Well sites are currently being considered with final service models being agreed in January 2009. These units will provide some residential respite. This will likely be focused on areas that are currently more difficult to commission – such as nursing or services for older people with mental health problems.
- The Carers Respite Emergency Support Service (CRESS) pilot is being extended. Over 500 users/carers have registered with this scheme which provides an emergency back-up plan should a carer be unable to maintain their caring role.
- Opportunities to provide respite care in a client's own home continue to be provided by the voluntary sector, funded through the Carers Grant.
- A new Strategic Commissioning Manager for Carers took up post in September. Their key role over the next six months will be to review and rewrite the Joint Carers Commissioning Strategy in the light of the new National Strategy: *Carers at the heart of 21st century families and communities: 'a caring system on your side, a life of your own' DoH June 2008.*
- As part of the national strategy, £150m nationally will be routed through Primary Care Trusts (PCT's) to provide additional residential respite. The details of this funding and operational details have yet to be announced.
- The number of complaints relating to residential respite is slightly lower (5 for the first 6 months to September 08) than last year (13 for the full year 2007-08). These range from issues relating to transportation to and from the service, to laundry services at the home. Levels of user/carers satisfaction are generally high.

3.3 The Committee is recommended to agree to receive an annual report to future meetings on:

1. The impact of PPF on respite provision
2. The development of the market to provide a wider range of services and the specific services to be provided through the Age Well PFI programme
3. The details of funding and implementation of the national carers strategy (particularly relating to respite)
4. The rewriting of the East Sussex Joint Carers Commissioning Strategy

Chief Officer: Keith Hinkley, Director of Adult Social Care

Contact Officer: Barry Atkins, Head of Strategic Commissioning 01273 482308

Local Member(s): All

Background documents: *Carers at the heart of 21st century families and communities: 'a caring system on your side, a life of your own' DoH June 2008*

						Data				
Supplier Sector	OP / WAA?	Client Group / Client Category For Service	Inception Date	Home Name / Supplier Name	Carer's Respite	No. of Clients	Average Duration	Percentage		
LOCAL AUTHORITY	OLDER PEOPLE	LEARNING DISABILITY	Pre April 2008	GILDA RESOURCE CENTRE	Yes	1	373	0.07%		
			June	GILDA RESOURCE CENTRE	Yes	1	21	0.07%		
			July	GRANGEMEAD	Yes	1	7	0.07%		
			September	GILDA RESOURCE CENTRE	Yes	1	7	0.07%		
		LEARNING DISABILITY Total						4	102	0.28%
		MENTAL HEALTH NEEDS			Pre April 2008	GILDA RESOURCE CENTRE	Yes	1	7	0.07%
						GRANGEMEAD	Yes	9	193	0.63%
						HOOKSTEAD RESOURCE CENTRE	Yes	4	9	0.28%
						MILTON COURT	Yes	2	7	0.14%
						MOUNT DENYS	Yes	1	42	0.07%
					April	GILDA RESOURCE CENTRE	Yes	1	7	0.07%
						GRANGEMEAD	Yes	13	24	0.90%
						MILTON COURT	Yes	5	7	0.35%
						MOUNT DENYS	Yes	9	34	0.63%
					May	39 HARVARD ROAD	Yes	2	40	0.14%
						GRANGEMEAD	Yes	9	11	0.63%
						HOOKSTEAD RESOURCE CENTRE	Yes	7	21	0.49%
						MILTON COURT	Yes	3	13	0.21%
						MOUNT DENYS	Yes	1	53	0.07%
					June	39 HARVARD ROAD	Yes	2	119	0.14%
						GRANGEMEAD	Yes	10	11	0.70%
						HOOKSTEAD RESOURCE CENTRE	Yes	5	26	0.35%
						MILTON COURT	Yes	1	62	0.07%
						MOUNT DENYS	Yes	1	121	0.07%
						ST ANTHONY'S COURT	Yes	1	17	0.07%
					July	39 HARVARD ROAD	Yes	2	10	0.14%
						GRANGEMEAD	Yes	12	13	0.83%
						HOOKSTEAD RESOURCE CENTRE	Yes	5	35	0.35%
						MILTON COURT	Yes	1	27	0.07%
						MOUNT DENYS	Yes	3	10	0.21%
						ST ANTHONY'S COURT	Yes	1	39	0.07%
					August	39 HARVARD ROAD	Yes	1	66	0.07%
						GRANGEMEAD	Yes	13	14	0.90%
						HOOKSTEAD RESOURCE CENTRE	Yes	7	25	0.49%
						MILTON COURT	Yes	1	4	0.07%
						MOUNT DENYS	Yes	4	17	0.28%

LOCAL AUTHORITY	OLDER PEOPLE	MENTAL HEALTH NEEDS	September	39 HARVARD ROAD	Yes	1	3	0.07%	
				GILDA RESOURCE CENTRE	Yes	1	33	0.07%	
				GRANGEMEAD	Yes	13	9	0.90%	
				HOOKSTEAD RESOURCE CENTRE	Yes	1	12	0.07%	
				MILTON COURT	Yes	1	7	0.07%	
			October	GRANGEMEAD	Yes	2	7	0.14%	
		MENTAL HEALTH NEEDS Total					156	30	10.85%
		OTHER VULNERABLE PERSON	April	MILTON COURT	Yes	1	7	0.07%	
				ST ANTHONY'S COURT	Yes	1	7	0.07%	
			June	GRANGEMEAD	Yes	1	50	0.07%	
				MILTON COURT	Yes	1	17	0.07%	
			July	MILTON COURT	Yes	1	74	0.07%	
			August	MILTON COURT	Yes	1	14	0.07%	
		OTHER VULNERABLE PERSON Total					6	28	0.42%
		PHYSICAL /SENSORY /FRAILITY	Pre April 2008	39 HARVARD ROAD	Yes	23	207	1.60%	
				GILDA RESOURCE CENTRE	Yes	14	146	0.97%	
				GRANGEMEAD	Yes	16	67	1.11%	
				HOOKSTEAD RESOURCE CENTRE	Yes	6	136	0.42%	
				MILTON COURT	Yes	5	202	0.35%	
				MOUNT DENYS	Yes	8	190	0.56%	
				ST ANTHONY'S COURT	Yes	14	244	0.97%	
			April	39 HARVARD ROAD	Yes	25	22	1.74%	
				GILDA RESOURCE CENTRE	Yes	17	34	1.18%	
				GRANGEMEAD	Yes	16	36	1.11%	
				HOOKSTEAD RESOURCE CENTRE	Yes	14	23	0.97%	
				MILTON COURT	Yes	14	24	0.97%	
				MOUNT DENYS	Yes	1	14	0.07%	
				ST ANTHONY'S COURT	Yes	9	32	0.63%	
			May	39 HARVARD ROAD	Yes	31	31	2.16%	
				GILDA RESOURCE CENTRE	Yes	20	14	1.39%	
				GRANGEMEAD	Yes	20	9	1.39%	
				HOOKSTEAD RESOURCE CENTRE	Yes	15	27	1.04%	
				MILTON COURT	Yes	15	15	1.04%	
				MOUNT DENYS	Yes	5	37	0.35%	
				ST ANTHONY'S COURT	Yes	15	29	1.04%	
			June	39 HARVARD ROAD	Yes	27	29	1.88%	
				GILDA RESOURCE CENTRE	Yes	14	31	0.97%	
				GRANGEMEAD	Yes	16	24	1.11%	
				HOOKSTEAD RESOURCE CENTRE	Yes	16	14	1.11%	
				MILTON COURT	Yes	15	9	1.04%	

LOCAL AUTHORITY	OLDER PEOPLE	PHYSICAL /SENSORY /FRAILITY	PHYSICAL /SENSORY /FRAILITY Total								
			June	MOUNT DENYS	Yes	7	38	0.49%			
				ST ANTHONY'S COURT	Yes	7	31	0.49%			
			July	39 HARVARD ROAD	Yes	32	23	2.23%			
				GILDA RESOURCE CENTRE	Yes	14	26	0.97%			
				GRANGEMEAD	Yes	15	13	1.04%			
				HOOKSTEAD RESOURCE CENTRE	Yes	11	24	0.76%			
				MILTON COURT	Yes	12	14	0.83%			
				MOUNT DENYS	Yes	3	7	0.21%			
				ST ANTHONY'S COURT	Yes	10	11	0.70%			
			August	39 HARVARD ROAD	Yes	30	16	2.09%			
				GILDA RESOURCE CENTRE	Yes	14	29	0.97%			
				GRANGEMEAD	Yes	14	11	0.97%			
				HOOKSTEAD RESOURCE CENTRE	Yes	18	9	1.25%			
				MILTON COURT	Yes	12	7	0.83%			
				MOUNT DENYS	Yes	7	6	0.49%			
				ST ANTHONY'S COURT	Yes	14	23	0.97%			
			September	39 HARVARD ROAD	Yes	18	20	1.25%			
				GILDA RESOURCE CENTRE	Yes	8	19	0.56%			
				GRANGEMEAD	Yes	25	14	1.74%			
				HOOKSTEAD RESOURCE CENTRE	Yes	13	18	0.90%			
				MILTON COURT	Yes	11	25	0.76%			
				MOUNT DENYS	Yes	2	4	0.14%			
				ST ANTHONY'S COURT	Yes	6	22	0.42%			
			October	39 HARVARD ROAD	Yes	1	6	0.07%			
				GILDA RESOURCE CENTRE	Yes	2	12	0.14%			
				GRANGEMEAD	Yes	3	8	0.21%			
				HOOKSTEAD RESOURCE CENTRE	Yes	2	9	0.14%			
				MOUNT DENYS	Yes	2	6	0.14%			
				ST ANTHONY'S COURT	Yes	2	8	0.14%			
			PHYSICAL /SENSORY /FRAILITY Total						706	39	49.10%
			UNKNOWN			Pre April 2008	HOOKSTEAD RESOURCE CENTRE	Yes	1	386	0.07%
						April	GRANGEMEAD	Yes	1	4	0.07%
							ST ANTHONY'S COURT	Yes	1	15	0.07%
						May	GRANGEMEAD	Yes	1	3	0.07%
							HOOKSTEAD RESOURCE CENTRE	Yes	1	7	0.07%
						June	GILDA RESOURCE CENTRE	Yes	1	3	0.07%
						July	39 HARVARD ROAD	Yes	1	36	0.07%
							GRANGEMEAD	Yes	1	34	0.07%
						August	39 HARVARD ROAD	Yes	1	15	0.07%
						September	GILDA RESOURCE CENTRE	Yes	1	13	0.07%

LOCAL AUTHORITY	OLDER PEOPLE	UNKNOWN	September	GRANGEMEAD	Yes	1	30	0.07%			
		UNKNOWN Total					11	50	0.76%		
OLDER PEOPLE Total						883	38	61.40%			
WORKING AGE ADULTS	LEARNING DISABILITY	Pre April 2008	GREENWOOD	Yes	3	203	0.21%				
				SANDBANKS	Yes	2	467	0.14%			
			April	GILDA RESOURCE CENTRE	Yes	1	3	0.07%			
				GREENWOOD	Yes	1	3	0.07%			
				SANDBANKS	Yes	1	2	0.07%			
			May	GREENWOOD	Yes	2	4	0.14%			
				SANDBANKS	Yes	2	33	0.14%			
			July	GILDA RESOURCE CENTRE	Yes	1	14	0.07%			
			LEARNING DISABILITY Total						13	126	0.90%
			PHYSICAL /SENSORY /FRAILTY	Pre April 2008	GILDA RESOURCE CENTRE	Yes	3	214	0.21%		
						ST ANTHONY'S COURT	Yes	2	215	0.14%	
					April	39 HARVARD ROAD	Yes	1	24	0.07%	
		GILDA RESOURCE CENTRE				Yes	1	6	0.07%		
		ST ANTHONY'S COURT				Yes	3	10	0.21%		
		May			39 HARVARD ROAD	Yes	1	28	0.07%		
					GILDA RESOURCE CENTRE	Yes	2	3	0.14%		
					ST ANTHONY'S COURT	Yes	3	4	0.21%		
		June			GILDA RESOURCE CENTRE	Yes	1	32	0.07%		
					ST ANTHONY'S COURT	Yes	2	55	0.14%		
		July			GILDA RESOURCE CENTRE	Yes	1	3	0.07%		
					ST ANTHONY'S COURT	Yes	1	2	0.07%		
					August	39 HARVARD ROAD	Yes	1	14	0.07%	
		GILDA RESOURCE CENTRE				Yes	1	3	0.07%		
		ST ANTHONY'S COURT				Yes	1	2	0.07%		
		September			39 HARVARD ROAD	Yes	1	34	0.07%		
					ST ANTHONY'S COURT	Yes	1	2	0.07%		
		PHYSICAL /SENSORY /FRAILTY Total						26	53	1.81%	
UNKNOWN	May	MOUNT DENYS			Yes	1	4	0.07%			
					Yes	1	4	0.07%			
					Yes	1	12	0.07%			
					Yes	1	4	0.07%			
					Yes	1	4	0.07%			
UNKNOWN Total						4	6	0.28%			
WORKING AGE ADULTS Total						43	71	2.99%			
LOCAL AUTHORITY Total						926	39	64.39%			
PRIVATE & VOLUNTARY	OLDER PEOPLE	EMI			Pre April 2008	AARON MANOR	Yes	1	7	0.07%	
			CLYDE HOUSE	Yes		2	28	0.14%			
			FARMSTEAD NURSING HOME	Yes		1	28	0.07%			

PRIVATE & VOLUNTARY	OLDER PEOPLE	EMI	Pre April 2008	GLOTTENHAM MANOR NURSING HOME	Yes	1	14	0.07%
				LINDSAY HALL NURSING HOME	Yes	1	14	0.07%
				LITTLE ACORNS	Yes	1	28	0.07%
			April	ASHLEY GARDENS RESOURCE CENTRE	Yes	2	16	0.14%
				FARMSTEAD NURSING HOME	Yes	1	14	0.07%
				FILSHAM LODGE	Yes	3	23	0.21%
				GLOTTENHAM MANOR NURSING HOME	Yes	3	11	0.21%
				HARECOMBE MANOR	Yes	1	14	0.07%
				HAVELOCK HOUSE	Yes	1	21	0.07%
				TUSKER HOUSE	Yes	1	3	0.07%
			May	ASHLEY GARDENS RESOURCE CENTRE	Yes	1	7	0.07%
				FILSHAM LODGE	Yes	1	70	0.07%
				JUBILEE COURT	Yes	3	14	0.21%
				LEOLYN NURSING HOME	Yes	1	7	0.07%
				TUSKER HOUSE	Yes	1	3	0.07%
			June	CEDARWOOD HOUSE	Yes	1	7	0.07%
				CLIFDEN HOUSE NURSING HOME	Yes	1	14	0.07%
				SPRINGCROFT NURSING HOME	Yes	1	14	0.07%
				SPRINGFIELD NURSING HOME	Yes	2	28	0.14%
				TUSKER HOUSE	Yes	1	14	0.07%
			July	THE PARK BECK	Yes	1	49	0.07%
				TUSKER HOUSE	Yes	1	2	0.07%
			August	CASTLEMAINE (BLOCK CONTRACT)	Yes	1	7	0.07%
				CEDARWOOD HOUSE	Yes	1	7	0.07%
				DUNSFOLD (HERSTMONCEUX)	Yes	1	3	0.07%
				ERSHAM HOUSE	Yes	2	35	0.14%
				FILSHAM LODGE	Yes	2	28	0.14%
				THE DERWENT RESIDENTIAL CARE	Yes	1	42	0.07%
				THE NORMANHURST	Yes	2	25	0.14%
			TUSKER HOUSE	Yes	2	10	0.14%	
			September	CEDARWOOD HOUSE	Yes	1	7	0.07%
				JUBILEE COURT	Yes	1	9	0.07%
				THE SHIRES	Yes	1	28	0.07%
TUSKER HOUSE	Yes	1		3	0.07%			
EMI Total						50	18	3.48%
OLDER PEOPLE	Pre April 2008	ABBAY HOUSE	Yes	1	57	0.07%		
		CEDARWOOD HOUSE	Yes	2	20	0.14%		
		CLAREMONT HOUSE	Yes	1	28	0.07%		
		FABEE NURSING HOME	No	1	0	0.07%		
		FOREST LODGE	Yes	1	83	0.07%		

PRIVATE & VOLUNTARY	OLDER PEOPLE	OLDER PEOPLE						
			Pre April 2008	HIGHBROOM CARE HOME	Yes	1	124	0.07%
				QUEEN MARYS LODGE NURSING HOME	Yes	2	34	0.14%
				ST PAULS NURSING HOME	Yes	1	7	0.07%
				ST VINCENTS RESIDENTIAL CARE H	Yes	1	42	0.07%
				THE CHASELEY TRUST	Yes	1	14	0.07%
				THE DEVONSHIRE NURSING HOME	Yes	1	32	0.07%
				THE HURST RESIDENTIAL HOME	No	1	0	0.07%
				WOODSIDE HALL NURSING HOME	Yes	2	16	0.14%
				ZZ_PENTLOW NURSING (BLOCK)	Yes	1	15	0.07%
			April	AARON MANOR	Yes	1	3	0.07%
				ABBAY HOUSE	Yes	1	14	0.07%
				ARDEN HOUSE	Yes	2	17	0.14%
				ASHLEY GARDENS RESOURCE CENTRE	Yes	3	33	0.21%
				BAY HOUSE	Yes	1	14	0.07%
				BETHUNE COURT	Yes	1	14	0.07%
				BRAMBLES RESPITE CARE HOTEL	Yes	2	7	0.14%
				CAMELOT RESIDENTIAL CARE HOME	Yes	1	28	0.07%
				CLYDE HOUSE	Yes	1	98	0.07%
				EDENDALE RESIDENTIAL CARE HOME	Yes	3	22	0.21%
				ELIZABETH COURT REST HOME	Yes	1	7	0.07%
				GLOTTENHAM MANOR NURSING HOME	Yes	2	2	0.14%
				HARECOMBE MANOR	Yes	2	33	0.14%
				HEALEY HOUSE	Yes	2	7	0.14%
				HELENSWOOD REST HOME	Yes	1	18	0.07%
				KENILWORTH	Yes	1	14	0.07%
				LAURISTON CHRISTIAN	Yes	1	6	0.07%
				LEOLYN NURSING HOME	Yes	2	14	0.14%
				PENTLOW NURSING HOME	Yes	3	12	0.21%
				PINEWOOD MANOR RESIDENTIAL	Yes	1	7	0.07%
				ROSELANDS	Yes	1	14	0.07%
				ST AUGUSTINES NURSING HOME	Yes	1	14	0.07%
				ST MARYS NURSING HOME	Yes	1	14	0.07%
				ST NECTANS RESIDENTIAL CARE HO	Yes	4	12	0.28%
				ST PETERS GRANGE	Yes	2	16	0.14%
				ST VINCENTS RESIDENTIAL CARE H	Yes	1	1	0.07%
				WESTERLEIGH NURSING HOME	Yes	1	19	0.07%
ZZ_ERSHAM HOUSE NURSING HOME	Yes	1	14	0.07%				
HARTFIELD HOUSE REST HOME	Yes	1	2	0.07%				
May	AARON MANOR	Yes	4	10	0.28%			
	ANCASTER COURT NURSING HOME	Yes	2	35	0.14%			

PRIVATE & VOLUNTARY	OLDER PEOPLE	OLDER PEOPLE						
			May	ARDEN HOUSE	Yes	1	1	0.07%
				ASHLEY GARDENS RESOURCE CENTRE	Yes	2	9	0.14%
				BENDIGO NURSING HOME	Yes	1	21	0.07%
				BETHUNE COURT	Yes	1	9	0.07%
				BIRCH HOLT RETIREMENT HOME	Yes	2	11	0.14%
				BRAMBLES RESPITE CARE HOTEL	Yes	1	7	0.07%
				FRESHFORD COTTAGE NURSING HOME	Yes	1	14	0.07%
				GLOTTENHAM MANOR NURSING HOME	Yes	2	9	0.14%
				HEATHERDENE NURSING HOME	Yes	1	11	0.07%
				INGLEWOOD NURSING HOME	Yes	3	29	0.21%
				KENILWORTH	Yes	2	18	0.14%
				LEOLYN NURSING HOME	Yes	2	18	0.14%
				MOUNTSIDE RESIDENTIAL HOME	Yes	1	3	0.07%
				PENTLOW NURSING HOME	Yes	2	7	0.14%
				PINEWOOD MANOR RESIDENTIAL	Yes	1	7	0.07%
				QUEEN MARYS LODGE NURSING HOME	Yes	2	18	0.14%
				ROSELANDS	Yes	1	9	0.07%
				ST AUGUSTINES NURSING HOME	Yes	1	3	0.07%
				ST NECTANS RESIDENTIAL CARE HO	Yes	5	20	0.35%
				ST PAULS NURSING HOME	Yes	2	7	0.14%
				ST PETERS GRANGE	Yes	5	22	0.35%
				THE CHASELEY TRUST	Yes	1	7	0.07%
				THE PARK BECK	Yes	1	28	0.07%
				THE WHITEBRIARS	Yes	2	36	0.14%
				THREEWAYS NURSING HOME	Yes	1	21	0.07%
				TREDEGAR NURSING HOME	Yes	1	14	0.07%
			June	AARON MANOR	Yes	4	9	0.28%
				ABBAY HOUSE	Yes	1	14	0.07%
				ANCASTER COURT NURSING HOME	Yes	4	20	0.28%
				ARDEN HOUSE	Yes	1	1	0.07%
				ASHLEY GARDENS RESOURCE CENTRE	Yes	1	17	0.07%
				BARONS DOWN NURSING HOME	Yes	1	28	0.07%
				BAY HOUSE	Yes	3	28	0.21%
				BENDIGO NURSING HOME	Yes	1	3	0.07%
				CHARDWOOD RESID CARE HOME	Yes	1	6	0.07%
				CREST HOUSE	Yes	1	7	0.07%
				CUMBERLAND CRT RES CARE HOME	Yes	1	7	0.07%
				ELIZABETH COURT REST HOME	Yes	3	19	0.21%
				GLOTTENHAM MANOR NURSING HOME	Yes	2	11	0.14%
				HEALEY HOUSE	Yes	2	11	0.14%

PRIVATE & VOLUNTARY	OLDER PEOPLE	OLDER PEOPLE							
			June	LAURISTON CHRISTIAN	Yes		1	14	0.07%
				LEOLYN NURSING HOME	Yes		1	0	0.07%
				LYDFORDS NURSING HOME	Yes		2	0	0.14%
				MOUNTSIDE RESIDENTIAL HOME	Yes		1	3	0.07%
				OLD HASTINGS HOUSE	Yes		1	28	0.07%
				PENTLOW NURSING HOME	Yes		2	44	0.14%
				PINEWOOD MANOR RESIDENTIAL	Yes		2	7	0.14%
				QUEEN MARYS LODGE NURSING HOME	Yes		5	19	0.35%
				ROSELANDS	Yes		2	12	0.14%
				ST PAULS NURSING HOME	Yes		3	7	0.21%
				ST PETERS GRANGE	Yes		4	14	0.28%
				THE DERWENT RESIDENTIAL CARE	Yes		3	42	0.21%
				THE POLEGATE NURSING CENTRE	Yes		1	13	0.07%
				TREDEGAR NURSING HOME	Yes		1	42	0.07%
			July	AARON MANOR	Yes		3	12	0.21%
				ANCASTER COURT NURSING HOME	Yes		3	19	0.21%
				ARDATH HOUSE	Yes		1	7	0.07%
				ARDEN HOUSE	Yes		1	1	0.07%
				BETHUNE COURT	Yes		2	12	0.14%
				BYBUCKLE COURT	Yes		1	14	0.07%
				CHENEYS	Yes		1	7	0.07%
				CLYDE HOUSE	Yes		1	28	0.07%
				ELIZABETH COURT REST HOME	Yes		1	7	0.07%
				FELIX HOLME	Yes		1	14	0.07%
				GLENMUIR HOUSE	Yes		1	56	0.07%
				GLOTTENHAM MANOR NURSING HOME	Yes		2	7	0.14%
				HARECOMBE MANOR	Yes		1	28	0.07%
				HEATHERDENE NURSING HOME	Yes		1	6	0.07%
				HILLERSDON COURT REST HOME	Yes		2	10	0.14%
				JUBILEE LODGE	Yes		1	7	0.07%
				LAURISTON CHRISTIAN	Yes		1	7	0.07%
				LEOLYN NURSING HOME	Yes		2	11	0.14%
				LONGWORTH HOUSE NURSING HOME	Yes		1	42	0.07%
				OLD HASTINGS HOUSE	Yes		3	16	0.21%
				PENTLOW NURSING HOME	Yes		2	14	0.14%
				PINEWOOD MANOR RESIDENTIAL	Yes		3	10	0.21%
				QUEEN MARYS LODGE NURSING HOME	Yes		2	18	0.14%
				RIDGEWOOD MANOR NURSING HOME	Yes		1	70	0.07%
				SPRINGFIELD NURSING HOME	Yes		1	14	0.07%
				ST AUGUSTINES NURSING HOME	Yes		1	21	0.07%

PRIVATE & VOLUNTARY	OLDER PEOPLE	OLDER PEOPLE	Month	Facility Name	Response	Count	Percentage	Percentage
			July	ST MARYS NURSING HOME	Yes	1	14	0.07%
				ST PETERS GRANGE	No	1	7	0.07%
					Yes	3	16	0.21%
				THE CHASELEY TRUST	Yes	2	14	0.14%
				THE DERWENT RESIDENTIAL CARE	Yes	1	42	0.07%
				THE PARK BECK	Yes	1	9	0.07%
				THREEWAYS NURSING HOME	Yes	1	14	0.07%
				WOODSIDE HALL NURSING HOME	Yes	9	37	0.63%
			August	AARON MANOR	Yes	3	6	0.21%
				ABBAY HOUSE	Yes	1	14	0.07%
				ANCASTER COURT NURSING HOME	Yes	2	42	0.14%
				ARDEN HOUSE	Yes	2	1	0.14%
				BARONS DOWN NURSING HOME	Yes	1	11	0.07%
				CHENEYS	Yes	1	28	0.07%
				CUMBERLAND CRT RES CARE HOME	Yes	1	7	0.07%
				ELIZABETH COURT REST HOME	Yes	2	3	0.14%
				ELSTREE COURT NURSING HOME	Yes	2	32	0.14%
				ERSHAM HOUSE	Yes	1	21	0.07%
				FARMSTEAD NURSING HOME	Yes	1	28	0.07%
				FOREST LODGE	Yes	1	28	0.07%
				GLOTTENHAM MANOR NURSING HOME	Yes	2	14	0.14%
				HAVELOCK HOUSE	Yes	1	28	0.07%
				HEALEY HOUSE	Yes	1	7	0.07%
				HILLERSDON COURT REST HOME	Yes	1	0	0.07%
				KENILWORTH	Yes	1	6	0.07%
				LAURISTON CHRISTIAN	Yes	1	7	0.07%
				LEOLYN NURSING HOME	Yes	4	12	0.28%
				LONGWORTH HOUSE NURSING HOME	Yes	1	16	0.07%
				MOUNTSIDE RESIDENTIAL HOME	Yes	2	9	0.14%
				NETLEY WATERSIDE HOUSE	Yes	1	7	0.07%
				OLD HASTINGS HOUSE	Yes	2	63	0.14%
				PINEWOOD MANOR RESIDENTIAL	Yes	2	7	0.14%
				QUEEN MARYS LODGE NURSING HOME	Yes	1	14	0.07%
				RIVENDALE LODGE EMI CARE HOME	Yes	1	56	0.07%
				ROSELANDS	Yes	1	14	0.07%
				ST AUGUSTINES NURSING HOME	Yes	1	14	0.07%
				ST PAULS NURSING HOME	Yes	1	7	0.07%
ST PETERS GRANGE	Yes	1	3	0.07%				
ST VINCENTS RESIDENTIAL CARE H	Yes	1	10	0.07%				
THE NORMANHURST	Yes	1	7	0.07%				

PRIVATE & VOLUNTARY	OLDER PEOPLE	OLDER PEOPLE	August	THREEWAYS NURSING HOME	Yes	3	26	0.21%
				TUSKER HOUSE	Yes	1	21	0.07%
				WOODSIDE HALL NURSING HOME	Yes	1	14	0.07%
				SHALOM REST HOME	Yes	1	7	0.07%
				ORCHARD HOUSE	Yes	2	6	0.14%
				GENSING REST HOME LTD	Yes	1	98	0.07%
			September	AARON MANOR	Yes	2	5	0.14%
				ANCASTER COURT NURSING HOME	Yes	1	28	0.07%
				ARDEN HOUSE	Yes	1	56	0.07%
				BETHUNE COURT	Yes	3	17	0.21%
				BIRCH HOLT RETIREMENT HOME	Yes	2	15	0.14%
				CHENEYS	Yes	1	28	0.07%
				DIAL HOUSE NURSING HOME	Yes	1	38	0.07%
				GLOTTENHAM MANOR NURSING HOME	Yes	1	15	0.07%
				HEALEY HOUSE	Yes	2	11	0.14%
				HEATHERDENE NURSING HOME	Yes	1	6	0.07%
				LENNOX LODGE	Yes	1	10	0.07%
				LEOLYN NURSING HOME	Yes	3	12	0.21%
				MOUNTSIDE RESIDENTIAL HOME	Yes	5	9	0.35%
				OLD HASTINGS HOUSE	Yes	1	14	0.07%
				PENTLOW NURSING HOME	Yes	2	9	0.14%
				PINEWOOD MANOR RESIDENTIAL	Yes	1	7	0.07%
				ST DOMINICS NURSING HOME LTD	Yes	2	18	0.14%
				ST HELENS HOUSE	Yes	1	14	0.07%
				ST PAULS NURSING HOME	Yes	1	7	0.07%
				ST PETERS GRANGE	Yes	4	13	0.28%
			THE CHASELEY TRUST	Yes	1	14	0.07%	
			THREEWAYS NURSING HOME	Yes	1	14	0.07%	
			ST JOSEPHS NURSING HOME	Yes	1	15	0.07%	
			October	AARON MANOR	Yes	2	35	0.14%
				BETHUNE COURT	Yes	1	14	0.07%
				HEALEY HOUSE	Yes	1	14	0.07%
				LAURISTON CHRISTIAN	Yes	1	7	0.07%
ST HELENS HOUSE	Yes	1		6	0.07%			
THE NORMANHURST	Yes	2		7	0.14%			
THE WHITEBRIARS	Yes	1	14	0.07%				
OLDER PEOPLE Total						329	18	22.88%
SUBSTANCE MISUSE			Pre April 2008	KENWARD TRUST	Yes	1	183	0.07%
SUBSTANCE MISUSE Total						1	183	0.07%
OLDER PEOPLE Total						380	18	26.43%

PRIVATE & VOLUNTARY	WORKING AGE ADULTS	EMI	Pre April 2008	FARMSTEAD NURSING HOME	Yes	1	284	0.07%		
		EMI Total					1	284	0.07%	
		LEARNING DISABILITY	Pre April 2008	NEW INN RESIDENTIAL HOME	No	1	0	0.07%		
				ROSEWOOD	Yes	1	183	0.07%		
				THE FORTUNE CENTRE OF RIDING T	Yes	1	243	0.07%		
				THE WELL HOUSE	Yes	1	2	0.07%		
			April	BEVERN VIEW	Yes	2	7	0.14%		
				MENCAP LUFTON MANOR COLLEGE	No	1	32	0.07%		
				THE FORTUNE CENTRE OF RIDING T	Yes	1	107	0.07%		
				THE WELL HOUSE	Yes	6	4	0.42%		
			May	BEVERN VIEW	Yes	2	5	0.14%		
				THE WELL HOUSE	Yes	5	2	0.35%		
			June	BEVERN VIEW	Yes	1	7	0.07%		
				MENCAP LUFTON MANOR COLLEGE	No	2	24	0.14%		
				THE WELL HOUSE	Yes	5	3	0.35%		
			July	BEVERN VIEW	Yes	2	8	0.14%		
				THE WELL HOUSE	Yes	5	4	0.35%		
			August	BEVERN VIEW	Yes	1	11	0.07%		
				THE WELL HOUSE	Yes	7	3	0.49%		
			September	THE WELL HOUSE	Yes	4	5	0.28%		
			LEARNING DISABILITY Total						48	16
		MENTAL HEALTH	April	LENNOX LODGE	Yes	1	7	0.07%		
			May	LENNOX LODGE	Yes	1	5	0.07%		
			June	XANDA HOUSE	Yes	2	9	0.14%		
			July	CORNFIELD HOUSE	Yes	1	77	0.07%		
				ELIZABETH COURT REST HOME	Yes	1	4	0.07%		
				LENNOX LODGE	Yes	1	6	0.07%		
August	LAWN COURT		Yes	1	11	0.07%				
September	LENNOX LODGE		Yes	1	6	0.07%				
	LANGLEY HOUSE		Yes	1	14	0.07%				
MENTAL HEALTH Total						10	15	0.70%		
OLDER PEOPLE	Pre April 2008	THE POLEGATE NURSING CENTRE	Yes	1	73	0.07%				
	April	GLOTTENHAM MANOR NURSING HOME	Yes	1	1	0.07%				
	May	ST HELENS HOUSE	Yes	1	83	0.07%				
		THE WELL HOUSE	Yes	1	10	0.07%				
		THREEWAYS NURSING HOME	Yes	1	7	0.07%				
	June	GLOTTENHAM MANOR NURSING HOME	Yes	3	19	0.21%				
		HARECOMBE MANOR	Yes	1	14	0.07%				
		PENTLOW NURSING HOME	Yes	1	14	0.07%				
	July	EGERTON ROAD	Yes	1	56	0.07%				

PRIVATE & VOLUNTARY	WORKING AGE ADULTS	OLDER PEOPLE	July	GLOTTENHAM MANOR NURSING HOME	Yes	4	39	0.28%
			August	BRAMBLES RESPITE CARE HOTEL	Yes	1	7	0.07%
				GLOTTENHAM MANOR NURSING HOME	Yes	1	9	0.07%
				NETLEY WATERSIDE HOUSE	Yes	1	7	0.07%
			October	PENTLOW NURSING HOME	Yes	1	9	0.07%
OLDER PEOPLE Total						19	27	1.32%
		PHYSICAL DISABILITY	Pre April 2008	NATIONAL STAR CENTRE	Yes	1	243	0.07%
				THE POLEGATE NURSING CENTRE	Yes	1	28	0.07%
			April	BRAMBLES RESPITE CARE HOTEL	Yes	1	14	0.07%
				GLOTTENHAM MANOR NURSING HOME	Yes	1	9	0.07%
				LEOLYN NURSING HOME	Yes	2	3	0.14%
				NATIONAL STAR CENTRE	Yes	1	95	0.07%
				SHINEWATER COURT	Yes	1	3	0.07%
				SKYLARKS	Yes	1	7	0.07%
				ST HELENS HOUSE	Yes	1	28	0.07%
				ST PETERS GRANGE	Yes	1	20	0.07%
				THE CHASELEY TRUST	Yes	3	9	0.21%
				THE WELL HOUSE	Yes	1	9	0.07%
			May	BRAMBLES RESPITE CARE HOTEL	Yes	2	7	0.14%
				CLYDE HOUSE	Yes	2	25	0.14%
				LEOLYN NURSING HOME	Yes	2	9	0.14%
				NETLEY WATERSIDE HOUSE	Yes	1	14	0.07%
				THE CHASELEY TRUST	Yes	1	21	0.07%
				THE WELL HOUSE	Yes	1	3	0.07%
			June	GLOTTENHAM MANOR NURSING HOME	Yes	1	14	0.07%
				ST PETERS GRANGE	Yes	1	28	0.07%
				THE CHASELEY TRUST	Yes	1	5	0.07%
			July	BRAMBLES RESPITE CARE HOTEL	Yes	2	7	0.14%
				GLOTTENHAM MANOR NURSING HOME	Yes	1	13	0.07%
				MILLSTREAM	Yes	2	28	0.14%
				NETLEY WATERSIDE HOUSE	Yes	1	14	0.07%
				THE WELL HOUSE	Yes	2	7	0.14%
			August	ST HELENS HOUSE	Yes	1	28	0.07%
				THE CHASELEY TRUST	Yes	2	4	0.14%
				THE WELL HOUSE	Yes	1	1	0.07%
			September	BRAMBLES RESPITE CARE HOTEL	Yes	3	7	0.21%
				DEVELOPMENT CENTRE	Yes	1	14	0.07%
				SHINEWATER COURT	Yes	1	21	0.07%
				THE CHASELEY TRUST	Yes	1	21	0.07%
			October	GLOTTENHAM MANOR NURSING HOME	Yes	1	14	0.07%

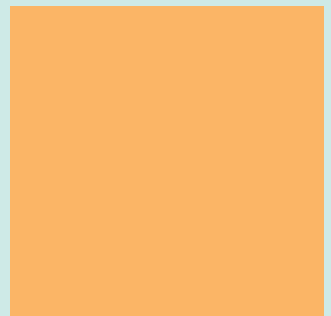
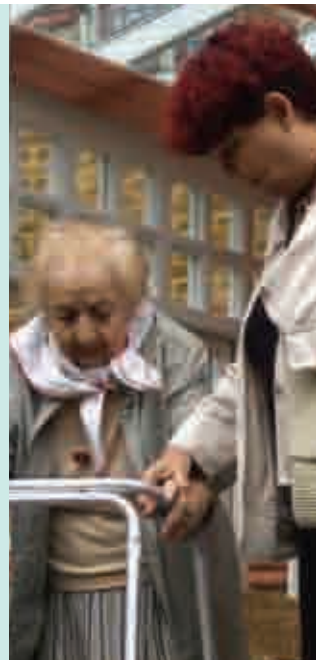
PRIVATE & VOLUNTARY	WORKING AGE ADULTS	PHYSICAL DISABILITY Total			46	19	3.20%	
		SUBSTANCE MISUSE	Pre April 2008	ANA	No	1	8	0.07%
				CARLTON HOUSE	No	1	84	0.07%
				DIANA PRINCESS OF WALES TREATM	Yes	1	84	0.07%
				JIGSAW	No	1	80	0.07%
				PHOENIX	Yes	1	183	0.07%
				PHOENIX HOUSE	Yes	1	84	0.07%
				PHOENIX HOUSE	Yes	2	38	0.14%
			SUBSTANCE MISUSE Total		8	75	0.56%	
		WORKING AGE ADULTS Total			132	24	9.18%	
PRIVATE & VOLUNTARY Total			512	20	35.61%			
Grand Total			1438	32	100.00%			



HM Government

Carers at the heart of 21st-century families and communities

**"A caring system on your side.
A life of your own."**



DH INFORMATION READER BOX

Policy	Estates
HR/Workforce	Commissioning
Management	IM & T
Planning	Finance
Clinical	Social Care/Partnership Working
Document purpose	Policy
Gateway reference	9971
Title	Carers at the heart of 21st-century families and communities
Author	HM Government
Publication date	10 Jun 2008
Target audience	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT PEC Chairs, NHS Trust Board Chairs, Directors of Finance, GPs, Communications Leads, Emergency Care Leads, Directors of Children's SSs
Circulation list	PCT CEs, NHS Trust CEs, SHA CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult SSs, PCT PEC Chairs, NHS Trust Board Chairs, GPs, Emergency Care Leads, Directors of Children's SSs, Voluntary Organisations/NDPBs
Description	The Carers Strategy sets out the Government's short-term agenda and long-term vision for the future care and support of carers
Action required	N/A
Timing	N/A
Contact details	Carers team Social Care, Local Government and Care Partnerships Directorate Department of Health 133-155 Waterloo Road London SE1 8UG 020 7972 4670
For recipient's use	



HM Government

Carers at the heart of 21st-century families and communities

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Department for
Innovation, Universities & Skills

Contents

PREFACE BY THE PRIME MINISTER	1
FOREWORD BY SECRETARIES OF STATE	4
EXECUTIVE SUMMARY	7
The Vision	15
Introduction	18
Chapter 1: Challenges, roles and responsibilities	30
Chapter 2: Integrated and personalised services	40
Chapter 3: A life of their own	69
Chapter 4: Income and employment	82
Chapter 5: Health and well-being	100
Chapter 6: Young carers	121
Chapter 7: Implementation	141
<i>Annex A: Putting People First</i>	148
Annex B: About the consultation	156
Annex C: Interdepartmental Group and Task Force membership	158

Preface





Caring for our relatives and friends when they are in need is a challenge that the vast majority of us will rise to at some point in our lives. At any one time 1 in 10 people in Britain is a carer – the majority of them, of course, still women. It is a testimony to the importance of families that so many of us are prepared to make the personal sacrifices that caring can involve in order to help our loved ones lead fulfilling lives even in the face of incapacity or disability. Our support and appreciation for carers is therefore not just fundamental to ensuring that those of us in need of care are able to receive it, but goes right to the heart of our values as a society and our ambition to create a fairer Britain.

Today, the demands both on our care system and on our carers themselves are greater than ever before – and they are set to continue to grow. So this strategy sets out the framework for developing support for carers not just as a one-off but as a progressive process of change over the next 10 years. It recognises the increasingly important role that carers play in our society alongside the wide variety of caring roles and the diversity of those within these roles, and it acknowledges that carers need more help and support than has been available in the past.

But above all this is a strategy based on the views and concerns of carers themselves. Through our Standing Commission on Carers and the many consultation events that we have held around the country, we are increasingly aware of the everyday challenges and obstacles that carers face.

Carers have told us they want a system that is on their side rather than one that frustrates them at every turn, including much more support to help them manage the twin demands of work and caring responsibilities. They want far more personalised support and greater scope to control and customise services, including in healthcare where identifying needs and ensuring prompt access to services can be so critical. And above all we recognise the need – repeated so many times throughout our

consultation – for better support for respite and short breaks. Too often carers are unable to access the kind of support which allows them to re-charge and renew themselves, and to address this we are taking immediate action to double our support for respite care over the next two years with an additional £150 million of new funding.

We have also heard and understood the request for us to do more to alleviate the financial hardships that all too many carers face, and as we look over the next year at the options for securing a better system of funding for all social care, we must also find the right approach to ensuring a fairer deal for our carers that provides financial support, particularly to those who face hardship.

These are the challenges we face, and this strategy is designed to help us meet them and to create a support system for carers that is fit for the 21st century. It is the start of a process rather than the end and I hope it will be welcomed by all carers as a platform from which we can build.

A handwritten signature in black ink, appearing to read "Amanda Berry". The signature is written in a cursive, flowing style.

Foreword by Secretaries of State



Every day 6,000 people take on new caring responsibilities, performing a crucial role in families and in their wider communities, by providing support, care and help with day-to-day tasks to those who otherwise would struggle to manage alone.

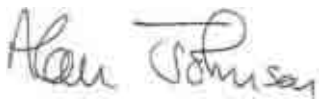
There is no fixed group that needs care. Support might be needed by relatives, friends, children, older people, people with disabilities or those who are ill. Caring has never been a sectional interest – everyone has the potential to become a carer, and it is likely that in the future more and more of us will. The number of people aged over 85 – the age group most likely to need care – is set to double over the next 20 years, affecting many more families. Traditionally caring has been seen as women’s work – and 70 per cent of it is still done by women but as our culture continues to change so too will this figure. Nine per cent of men now have caring responsibilities compared with 11 per cent of women. Caring is increasingly part of all our lives.

People who care do so because they want to help the people they care about, but often it means they end up juggling the support they give with other responsibilities, in a difficult balancing act. For many carers, looking after their own health, combining caring with work, getting access to training or simply having time to take a break and go away for a weekend can be a major challenge. People who provide a lot of care tend to have lower incomes, poorer health, and are less likely to be in work than their counterparts.

If carers are to have the same opportunities as everyone else in society, and to be able to have a life outside caring, we need to improve support and recognition for what they do. That means improving health and social care support, ensuring that carers are able to access education and leisure opportunities, and making sure that people with caring responsibilities have the chance to work flexibly so as to combine work with their caring roles. For the many children and young people who support parents or other family members it means making sure that they are not providing unreasonable levels of care, and that they have the support they need to learn, to develop and to thrive.

This strategy sets out the action we plan to take, working with partners and, building on the progress made by our first ever carer's strategy, *Caring for Carers*, published in 1999.

Responding to the needs of the growing numbers of people who care is one of the major challenges we face as a result of the demographic changes underway today. We must work together using the 10-year framework set out in this strategy to ensure that this challenge is met.



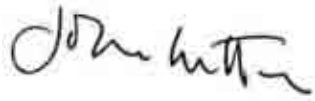
Alan Johnson
Department of Health



Hazel Blears
Communities and
Local Government




James Purnell
Department for Work
and Pensions



John Hutton
Department for
Business Enterprise
and Regulatory
Reform



Ed Balls
Department for
Children, Schools
and Families



Harriet Harman
Government Equalities
Office



John Denham
Department for
Innovation, Universities
and Skills

Executive summary



Carers are at the heart of 21st-century families and communities. In a changing society most people are living longer, many are developing long-term clinical conditions and the vast majority have rising aspirations in terms of maintaining maximum independence and control over their own lives. Consequently, an increasing number of us may find ourselves taking on a caring role at some point in our lives.

Many people, mainly women, are now balancing work, childcare and caring for an ageing parent. Increasing numbers of older people often care for their partner while providing childcare for grandchildren, and parents of children with complex health needs know that they will be 'lifetime' carers. Furthermore, the positive shift to independent living and care at home, away from institutionalisation, will continue to require a greater contribution from carers. At the same time families are now frequently scattered across the world, couples are struggling to retain a positive work-life balance and in an ageing society, some older people are left isolated with little or no support from family or friends.

These changes mean that the needs of carers must, over the next 10 years, be elevated to the centre of family policy and receive the recognition and status they deserve.

Twenty years ago there was little or no recognition of the contribution and distinct needs of carers. Since the 1999 Prime Minister's Carers' Strategy there has been significant progress, including an annual Carers Grant to every local authority in England, the right to request flexible working and enhanced pension entitlements. Most recently, the *Aiming high for disabled children* programme will result in greatly enhanced support for families with disabled children.



FACTBOX

Funding to date and in the future

By March 2011, we will have invested over £1.7 billion for councils to use to support carers in a range of ways through the annual Carers Grant. This includes £25 million a year announced as part of the New Deal for Carers for the emergency break provision.

We have also committed a further £22 million to cover the costs of the establishment of information services via a helpline and a training programme for carers and information service, and £3.4 million to directly support young carers through extended Family Pathfinders and support for whole-family working.

We are now investing over £255 million on new commitments as part of this strategy.

However, the next decade must lead to major and substantial change in the everyday lives of carers and the family members and friends they support. This new deal alongside the *Independent Living Strategy*, the social care reform programme set out in *Putting People First*, the long-term reform of the care and support system, NHS reforms, reforms within children's services and welfare reform, must ensure carers experience a system which is on their side rather than enduring a constant struggle so that they are supported to have a life of their own alongside their caring responsibilities.

Our vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.

By 2018:

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;

- carers will be able to have 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.

This is a shared vision and responsibility between central and local government, the NHS, the third sector, families and communities. It has been shaped by the thousands of carers, their advocates and front-line support staff, who have told us what matters most if we are truly to ensure that carers have the best possible quality of life and recognition that they deserve.

The action we will take to transform this from a vision to a reality over the next 10 years covers issues including breaks, income, information and advice, the workplace, training for the workforce, access to employment, emotional support, the health of carers and the specific needs of young carers.

Short-term changes will begin this year and be implemented over the next three years. Longer-term priorities are identified that will ensure we achieve our 2018 vision. We will consult with carers, their advocates and stakeholders on a timescale for their implementation, taking account of new advice and available resources.

2008–11: Commitments

Commitments

Information and advice

- Providing every carer with the opportunity to access comprehensive information when they need to. The information will be easily accessible for all groups of carers, and specific to their locality.

New break provision

- £150 million to significantly increase the amount of money provided by central government for breaks from caring for carers. This money will be provided in a flexible way, which meets the personal needs of carers and the people that they support;
- Pilots will help to develop models of break provision that demonstrate the cost-effectiveness of breaks and help identify what constitutes high-quality provision based on carers' needs.

Expanded NHS services

- Pilots to look at how the NHS can better support carers in their caring role through developing models of best practice and enabling more joined-up service provision between the NHS, local authorities and the third sector;
- Pilots to improve the support offered by GPs for carers;
- Piloting annual health checks for carers.

Employment and skills

- Up to £38 million to enable carers to be better able to combine paid employment with their caring role and re-enter the job market after their caring role has ended through encouraging flexible working opportunities and increased training provision.

Emotional support

Improving the emotional support offered by central, local government and the third sector to carers.

Young carers

Over £6 million to ensure young carers are protected from inappropriate caring and receive the broader support they need. Through:

- strengthening support from universal and targeted services;
- strengthening the quality and join-up of support around families so children are better protected from inappropriate caring.

Expert partners in care

- Training carers to enable them to strengthen them in their caring role and to empower them in their dealings with care professionals.

Workforce

- Training professionals across the board, from health to housing, to provide better services and support for carers.

Third sector

- Ensure that third sector support for carers is available throughout the country to a larger proportion of carers than is currently reached.

Information about carers

- Provide vital data about carers to aid commissioners and policy makers at a local and national level in providing better support for carers;
- Establishing a standard definition of carers across government.

Total investment over 2008–11: over £255 million in addition to over £22 million previously committed



2011 onwards: Identified priorities

Identified priorities

Services

- Carers able to access specialist carers' services in every community.

Personalisation agenda

- Consider extending flexibility in the way personal budgets and direct payments can be used.

Easy-to-access support

- Where appropriate, carers offered a lead professional to help access services and ensure early intervention when circumstances change.

Income

- Review the structure of the benefits available to carers in the context of wider benefit reform and the fundamental review of the care and support system.

New break provision

- Consider further increases to break provision taking account of evidence about quality and outcomes;
- Disseminate models of best practice on quality and innovative approaches to break provision based on the evidence garnered in the pilots.

Expanded NHS services

- Disseminate models of best practice to primary care trusts (PCTs) on how to provide better support for carers;
- Develop a full training package for all GPs, dependent on the results of the pilots;
- Consider providing carers across the country with annual health checks;
- Consider providing replacement care for carers to attend hospital appointments and screenings;
- Discuss with GPs and other health professionals the measures that can be taken that will provide a sharper focus on the distinct needs of carers.

Young carers

- Ensure protections for young carers are fully embedded: further measures to be considered in the light of research findings over the next two years.

Expert partners in care

- Work to establish the legislative or other requirements needed to enable carers to receive appropriate information, especially in cases where mental capacity is an issue.

Information about carers

- Review the national indicator set to ensure that carers' experience of services is measured.

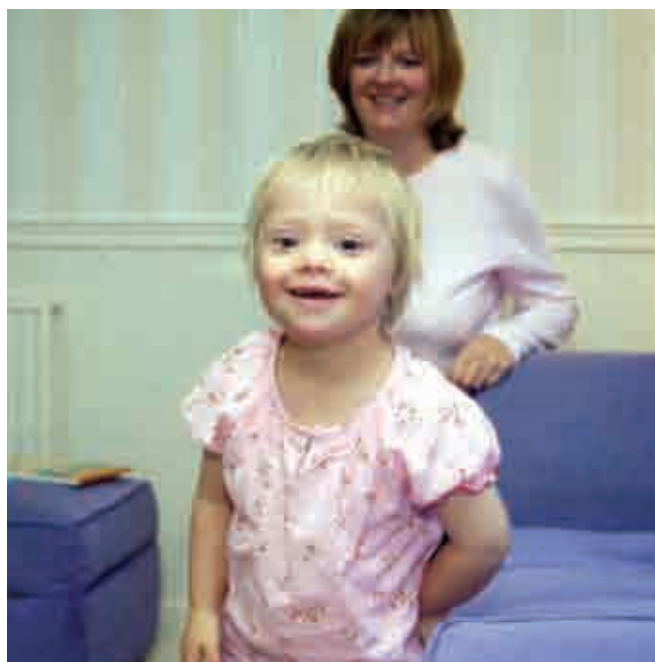
Annual Carers Grant

- In the context of community empowerment and the reform of the care and support system, we will 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.

The success of this transformational New Deal for Carers will depend on the commitment and vision of statutory, third and private sector agencies. In all cases they will need to engage with individual carers, the people that they support and carers' networks in a new way – which recognises that it is carers who are best placed to articulate their own aspirations as well as the emotional and practical realities of their caring experiences.

Over the next 10 years, it is carers who will judge the effectiveness of this strategy. It is they who will know whether they feel valued, respected and supported to have the best possible quality of life, often in difficult circumstances.

The Vision



Our vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.

By 2018:

- carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;
- carers will be able to have 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*¹ outcomes.

This is the vision for the future of carers shared by all – central and local government, the third sector and most importantly, carers themselves.

Taking this from a vision to a reality over the next 10 years will require changes and attention on issues including breaks, income, information and advice, the workplace, access to employment, emotional support, the health of carers and the specific needs of young carers.

Short-term changes will begin this year and be implemented in every part of the country over the next three years. We have also identified longer-term priorities that will help to achieve our 2018 vision. We will consult with carers, their advocates, the people that they support, and stakeholders, taking into account their views, other policy developments and available resources when developing a timescale for implementation.

Underlying our approach is a recognition of the need to get the services right for the person being supported. Carers and their caring role are inextricably linked to the people they care for. If the support and services are not right for the person being supported then both the individual and the family are affected.

Putting People First,² the *Independent Living Strategy*³ and the review of the Care and Support system⁴ are at the forefront of our move towards a single community-based support system focused on the health and well-being of the local population. This strategy is an integral part of this agenda for providing better care and support for individuals and families.

2 *Putting People First: A shared vision and commitment to the transformation of adult social care*, HM Government, 2007

3 *Independent Living: A cross-government strategy about independent living for disabled people*, Office for Disability Issues, 2008

4 *The Case for Change – Why England needs a new care and support system*, HM Government, 2008

Introduction



This strategy sets the agenda for supporting carers over the next 10 years ranging across the span of government's responsibilities. It addresses health and social care and young carer issues in England and income and employment matters more widely across the whole of Great Britain.

We have held a comprehensive consultation to ensure that the strategy has had the fullest engagement of those who know what it is like to devote a significant proportion of their time to caring for a loved one or friend.

This chapter sets out who we define as carers, the major legislative and policy changes since 1999 and provides details of the consultation.

Who are carers?

Across government, the term 'carer' has different meanings in different pieces of legislation.

A carer spends a significant proportion of their life providing unpaid support to family or 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. We will carry out a full review and impact assessment of this definition to see whether it or another could be adopted across government. However, we recognise, of course, that there might still be certain trigger points before an entitlement to benefit or flexible working come into effect.

Carers are not a homogenous group. Caring can take a large number of forms and is undertaken by individuals from all walks of life at different stages in their lives. Importantly caring involves, or has the potential to involve, each and every one of us.

The experience of caring will differ, of course, according to the circumstances of the person cared for, and the cultural expectations and family structures within different communities. In addition, there are some groups of carers about whom little is known due to difficulties in identifying them at a national and local level, for example those with learning disabilities, and lesbian, gay, bisexual and transgender (LGBT) carers.

Caring for an elderly relative

William (86) cares for his wife, Emily (84), who has Alzheimer's disease. He has cared for her for many years. The local specialist mental health team for older people co-ordinate care and support from a variety of agencies.

Emily needs help with all aspects of daily living, and care workers assist her each morning and evening. Emily attends a day centre twice a week, specifically for older people with dementia, and stays in a residential home with a dementia care unit every few weeks, to give her husband a break.

An occupational therapist has assisted with a ramp to their home and a psychiatrist sees Emily every six months, to monitor progress. A community psychiatric nurse is also involved in Emily's care. There is additional support from a carers' support worker from Age Concern.

William has a lot of support from the County Carers organisation (which has offered training in moving and handling Emily, and dealing with emotional stress) and the local Alzheimer's Society. William is now seeking support with helping Emily in and out of the car, as this is becoming increasingly difficult.

CASE STUDY

Young carers

Danielle (8) and Petra (10) are sisters. Their mother, Ella, has a history of anxiety, which has recently become so severe that she no longer feels able to leave the house. Their father has a full-time job that involves long hours and he is now the only breadwinner. He has found it difficult to understand Ella's illness. Danielle and Petra often miss school, as they do not want to leave their mother alone in the house. On one occasion, Danielle and Petra came home and found Ella unconscious after she had taken an overdose. Petra rang for an ambulance and looked after Danielle until it came.

The school is aware that Ella is ill, as the children often stay at home so that she is not left alone during the day, but the family have not wanted to share any further details. Some of the teachers are more understanding than others about late or unfinished homework. The girls do not want their friends to find out about their mum and are quite withdrawn at school, occasionally experiencing bullying as a result.

CASE STUDY

Mutual caring

Elsie (88) lived at home with her daughter, Christine (60), who has a learning disability. They lived together all their life and they did everything together. Christine was declared “uneducable” at the age of six and Elsie was told to “take Christine home and keep her happy”. Christine did not use any services until she was 40 when her dad had a stroke and Elsie found herself suddenly caring for two people. However, Christine really enjoyed the new activities and the contacts that the services brought. As they both grew older, Christine did more and more things to help her mum, who found tasks like carrying the shopping increasingly difficult.

When Elsie was diagnosed with a terminal illness, both Elsie and Christine had full needs and carers’ assessments as they were looking after each other. Services were offered to support Elsie when Christine was not at home, and to help Christine with things like cooking, cleaning and shopping for them both. Although Christine sometimes found it very difficult to care for her mum and watch her illness worsen, it was very important to both her and Elsie that they stayed together for as long as possible and she is proud of the care she provided while her mother was still alive. She says: *“Mum always looked after me and I’m glad I could look after her too because I know how she liked things done.”*

CASE STUDY

Intergenerational caring

Ajmir (17) has cerebral palsy. He is unable to speak and uses British Sign Language (BSL).

His mother Kim is the main carer, and her husband Sarvjit helps when he can. Both parents work full-time, so three days a week, Ajmir attends a residential school. When at home, he has two daily visits from a local homecare provider, helping him to bathe and dress, and in the evening, get ready for bed. The homecare worker has learned signs in BSL, and some key words in Punjabi. She has learned about the Sikh religion and culture in order to show the family that she understands their culture.

Sarvjit's frail and elderly parents live next door. Kim and Sarvjit care for them too, taking them to clinical appointments. However, the grandparents have a caring role with Ajmir too, supporting him when his parents go out. Ajmir is also able to reciprocate their help, assisting his grandparents by undertaking simple tasks for them such as putting the dishes away or closing windows.

During the summer holidays, Ajmir, with support from his family, uses his direct payment to purchase care, which provides a break for Kim.

CASE STUDY

When considering carers we also need to be aware of the significant numbers of carers who do not identify themselves as such. For example:

- cultural concepts of caring are not universally shared throughout communities in Britain; many people from other countries do not have experience of a welfare state and therefore, among a whole range of concepts, would not understand the concept of a 'carer'.⁵ The National Black Carers and Carers Workers Network have highlighted that they have been unable to find a word in Gujarati, Urdu, Punjabi or Bengali which translates into 'carer';
- parents of disabled children understandably often see themselves as parents rather than carers, but this can mean that they lose out on valuable support available to them;
- older couples who see caring for each other as a natural part of their lives and of being together 'in sickness and in health';
- people caring for a family member or friend as a result of substance misuse – who often don't see themselves as eligible for carers' services.

"I am a husband, a parent, a nurse, a chauffeur, a receptionist, a translator, a counsellor, a mediator; I never did realise I was a carer until someone told me I was." (Carer at a recent conference)

FACTBOX

- Although the gap in care provision between men and women is closing, women remain more likely to provide personal and heavy-duty care.⁶
- Bangladeshi and Pakistani groups are more likely to be carers than any other ethnic group.⁷

5 *Beyond We Care Too* – Putting black carers in the picture, National Black Carers and Carers Workers Network, 2008

6 Office for National Statistics, 2006

7 Characteristics of care providers and care receivers over time, Joseph Rowntree Foundation, 2006

Where are we now – beyond the first strategy

Caring about Carers had two important outcomes. First and foremost, its publication raised the profile of carers – it made improving the lives of carers a major policy issue and one of the Government’s key priorities. Secondly, by recognising the important role that carers play in supporting family members, friends and wider society, the strategy began a journey towards improved support for all carers.

Key achievements since 1999 include the introduction of the Carers Grant to help local authorities in England increase the level of support that they provide to carers, particularly through the provision of planned breaks. These can sometimes be for carers on their own or sometimes for carers and the people for whom they care – depending on individual circumstances. Since its introduction in 1999 the grant, which stands at £224 million in 2008/9 and is due to rise to £256 million in 2010/11, has provided over £1 billion of additional support to local councils.

Caring about Carers also highlighted the importance of accurate, up-to-date and comprehensive information to support carers so that they could become better aware of their entitlements, and of the sorts of relevant support available in their locality.

Legislative changes

As well as providing additional financial support to local authorities, the Government has supported two major pieces of legislation and introduced two more which have impacted directly on carers’ lives. Firstly, the **Carers and Disabled Children Act 2000** made four principal changes to the law:

- councils were given powers to support carers by providing services to carers directly;
- carers were given the right to an assessment independent of the person they care for;
- local authorities were enabled to make direct payments to carers;
- councils were given options to support flexibility in provision of short breaks through the short-break voucher scheme.

The second piece of legislation was the **Carers (Equal Opportunities) Act 2004**, which made three main changes to the existing law around carers' services:

- there is now a duty on councils to inform carers, in certain circumstances, of their right to an assessment of their needs;
- when assessing a carer's needs, councils must now take into account whether the carer works or wishes to work, undertakes or wishes to undertake education, training or leisure activities;
- there should be co-operation between authorities in relation to the provision of services that are relevant to carers.

The **Work and Families Act 2006** extended the right to request flexible working to employees who care for adults. This built on the introduction (through the **Employment Act 2002**) of the right to request flexible working for parents of children under the age of six (or 18 if the child is disabled). Imelda Walsh's independent review⁸ has now recommended that the right to request flexible working should be extended to cover parents of children aged 16 and under. We have welcomed her recommendations and we will consult on the recommendations made in the review.

Finally, legislation on equalities and the **Disability Discrimination Act(s)** recognises the right of people in society to equal citizenship, which will benefit both carers and the people that they care for and support.

Our health, our care, our say⁹

In 2006, the community services White Paper *Our health, our care, our say* announced a New Deal for Carers made up of four constituent parts, of which this strategy is the centrepiece.

- i) **A comprehensive national information service** that meets the many and diverse needs and concerns of carers. The service will provide, via a single telephone number and a website, access to the information needed by carers. Carers will be provided assistance by the service directly, or referred onto more appropriate support.

8 *Right to Request Flexible Working: A review of how to extend the right to request flexible working to parents of older children*, Department for Business, Enterprise and Regulatory Reform, 2008

9 *Our health, our care, our say: A new direction for community services*, Department of Health, 2006

This single information provision will work in conjunction with other similar services to ensure full integration with the various information facilities available to carers, thus giving a better value of service delivery. It will also ensure that information can be provided in formats suitable for those with disabilities or limited English.

The service, for which we are making £2.775 million per year available, will be in place in spring 2009.

- ii) **The establishment of Caring with Confidence,¹⁰ a training programme for carers**, which recognises that the caring role is often taken on suddenly and without preparation, leaving carers to struggle with the vital responsibilities they have assumed. The programme will provide training to carers, empowering and enabling them in their caring role. It will inform them of their rights, the services available to them and provide information and training that will benefit the whole family. It will also develop their advocacy skills and their ability to network with other carers to support their needs.

The training will be available on a face-to-face basis from August 2008 and, on a distance-learning basis, from December 2008. We are making £4.6 million per year available to fund the programme.

- iii) **Emergency care cover.** £25 million additional funding per year was made available from October 2007 to local authorities – to enable them to develop plans with carers to provide cover when the carer experiences an emergency that prevents them from caring. Whenever possible, this should be in the person cared for's own home. Guidance has been issued to local authorities setting out the intention for which the funding was made available. The guidance stresses the need to work with carers and the people they support in developing plans and is therefore a further building block in the development of the personalisation agenda.

¹⁰ This was originally announced as the *Expert Carers Programme*. However, in consultation with carers we have changed this to the new title – *Caring with Confidence*

- iv) **An updated Prime Minister's Strategy for Carers.** While *Caring about Carers* set the direction of travel for raising the profile of carers and provided an important first step towards improving the support and recognition that carers need, it did not set out to provide the framework for meeting all of their needs. It is the purpose of the new strategy to develop this further and to set the vision for the next 10 years, supported by a set of commitments designed to achieve that vision.

The process for developing the strategy

Public consultation

To identify measures and changes that would make the most significant improvements to carers' lives, we announced "the most far-reaching consultation on the future of carers ever". The consultation involved a web-based "ideas tree", a large number of local events based around the ideas tree and nine regional events. It culminated in three deliberative events and a final consultative event. It sought the views of carers from a wide variety of groups, including black minority and ethnic (BME) groups, parent and young carers.

The total period for consultation lasted for six months and we received views from over 4,000 carers.

Further details of the consultation process and its findings is contained in Annex B.

The Task Forces

To supplement the public consultation outlined above, we also set up four task forces to consider key aspects of the new strategy (a list of task force members can be found in Annex C). These were:

- Employment;
- Equalities;
- Health and Social Care;
- Income;

An Interdepartmental group, which included key stakeholders, oversaw the work of the Task Forces (a list of members is attached at Annex C).

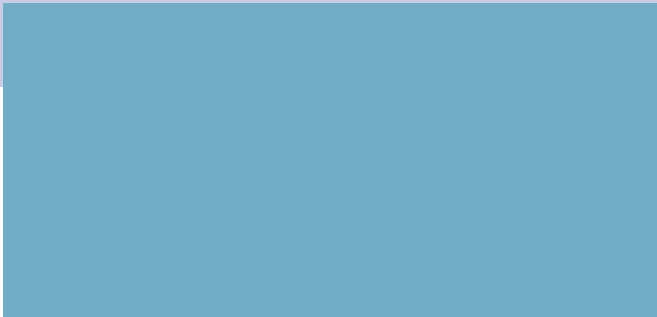
Standing Commission on Carers

Finally, we announced a new Standing Commission on Carers in September 2007. The Commission has a long-term remit, which includes a key role in the implementation of the strategy as well as a responsibility to advise the Government on matters it feels are relevant to carers in the longer term.

The Commission, chaired by Dr Philippa Russell CBE, has been closely involved in the development of the strategy.

The Commission will ensure that the voice of carers is kept at the very heart of government after the strategy has been published. We intend that the Standing Commission should be an influential and powerful advocate for carers both within government and with external stakeholders, and that they will work with carers across the country to ensure that their voice is heard at a local and national level.

Chapter 1: Challenges, roles and responsibilities



- 1.1** This document represents the latest step in our continued focus on carers over the last 10 years. It builds on the publication of the first Prime Minister's strategy, *Caring about Carers*, in 1999. In simple terms, its aim is to set a framework that will drive improvements in the support carers receive.
- 1.2** The strategy sets the agenda for the next 10 years for improving the lives of those who care for ill, frail or disabled friends or relatives (including those with mental health and substance misuse problems). We set out commitments covering the short and longer terms – to the end of the current spending review ending in March 2011 and beyond respectively. In doing so we tackle one of the key issues facing society today – how to establish the parameters and responsibilities for providing care for the growing number of people who need support, while taking account of an individual's needs and being realistic about what is appropriate for statutory services to provide.
- 1.3** The strategy focuses on personalised services, that is services that support people and their carers in their own homes and communities to the maximum degree possible. This fits with the key aims of our wider personalisation agenda, of which this strategy is a part.
- 1.4** Above all, in setting out this strategy we are providing the framework to improve the support that carers receive, to enable them to maintain a balance between the provision of care and a healthy life outside of caring.
- 1.5** The progress made since publishing *Caring about Carers* has already been summarised in the introduction. However, there is still much we can do to improve the support that we know carers need if they are to be able to continue providing this invaluable service to society. The key challenges that this strategy addresses are contained in The Vision. However, these need to be delivered in a way that takes full account of the demographic challenges facing society today.

Changes in the population

- 1.6** Over the next 10 years, there will be significant demographic and social changes in Britain presenting major challenges to government and society. In a world where, through advances in technology and medicine, people survive with complex health conditions, live longer

and have multiple needs, the demand for care will continue to grow. Changes in family life, increased numbers of single-member households and geographical dispersion within families, may also have an impact on the availability of carers.

FACTBOX

The number of people over 85 in the UK, the age group most likely to need care, is expected to increase by over 50 per cent to 1.9 million over the next decade.¹¹

- 1.7** Improvements to life expectancy and the ability to participate in society are to be celebrated, but we need to reflect these changes in our future plans. This carers' strategy must take full account of the future need for care and support, while also recognising the carer's wish to be able to combine paid employment and caring as well as having a life outside of caring. For young carers specifically, it must also ensure their opportunity to enjoy their childhoods and to learn, develop and thrive as other children do is properly protected.
- 1.8** While much can be done to improve support for carers within existing resources, inevitably there are some areas where additional central and local government spending will be needed. In setting the framework for the future we have tried to recognise the duties and responsibilities of the state and to ensure that they are properly and fairly discharged. But we also need to realise the limitations of what the state can do and reach an understanding of where the role of the family, the individual and wider society begins. Finally, any realistic solution to the challenge of improving carers' lives must recognise that the individual, family and state must work in partnership. The nature of the relationship between the individual, family and state is to be considered as part of the review now underway on the future of the care and support system.

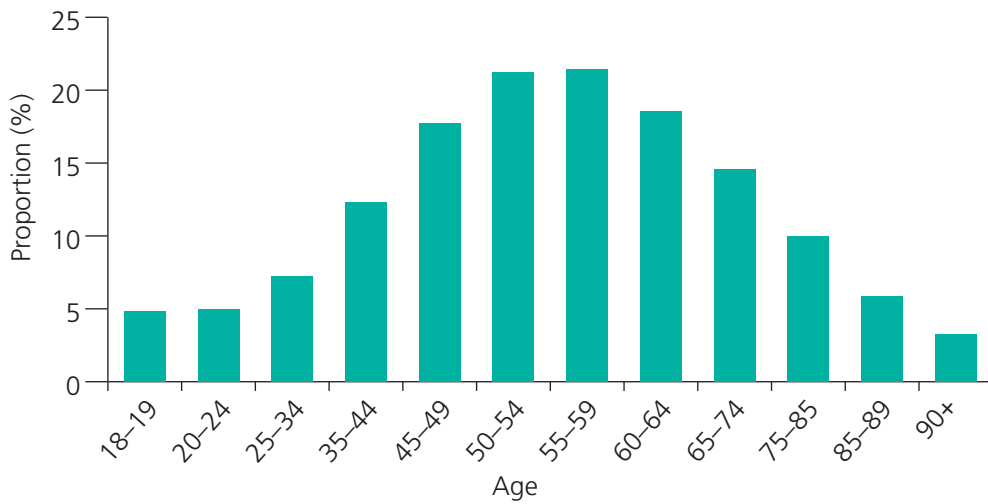
Care, support and independence: meeting the needs of a changing society

- 1.9** The changes outlined above taken together demonstrate the growing challenge posed by the increase in the number of people needing care, and the ready availability of those friends and family members who are able to provide it. Facing up to the challenge is crucial, because our society depends to a large degree on the continuation of the care that carers provide. There needs to be an open and honest debate about the appropriate balance of responsibility between the family, the individual and the Government if England is to have a sustainable care and support system.
- 1.10** The long-term challenge is to create a new settlement between individuals, family and the state that will be sustainable in the future. We think the principle of sharing costs between the family, the individual and the Government is right. However, we must avoid overstressing families and individuals, and believe that it is worth exploring how all adults could contribute in a way that is affordable for them, and that also protects them against facing very high care and support costs.
- 1.11** As part of *The case for change: Why England needs a new care and support system*, we want to examine the potential sources of care with the public and stakeholders, and debate the appropriate levels and balance of contributions from each source. We have asked key questions such as:
- How much care is it appropriate for families to undertake?
 - How do we take account of the fact that families will have different capacities to provide support and a range of competing demands on their time?
- 1.12** The answers to these questions will then inform the development of the Care and Support Green Paper, which is due to be published early in 2009.

Characteristics of Caring

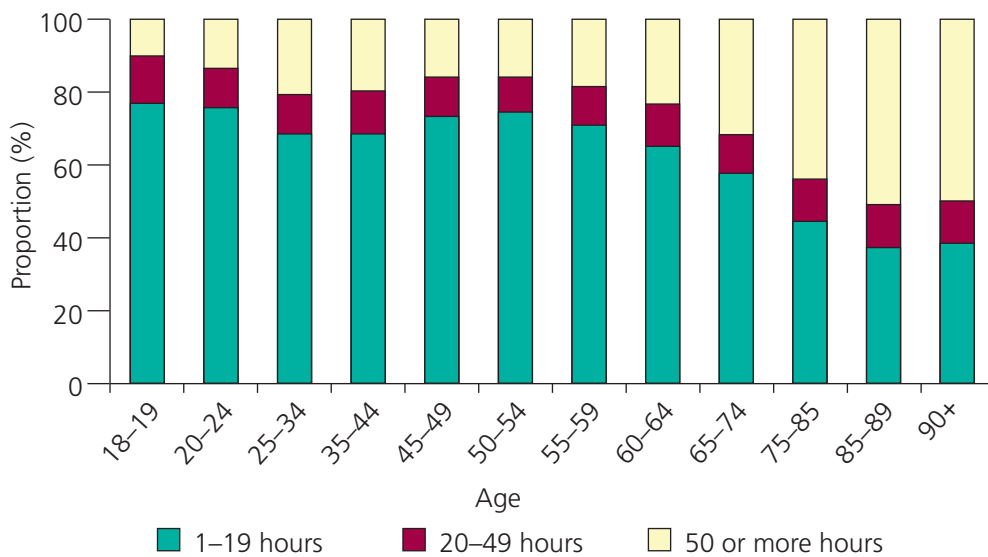
- 1.13** The 2001 Census found that there were 5.2 million carers in England and Wales, with over 1 million people caring for over 50 hours per week. However, there is no average profile of a carer with caring being taken on across all age groups, ethnic groups and geographic locations.

Figure 1: Percentage of age group caring



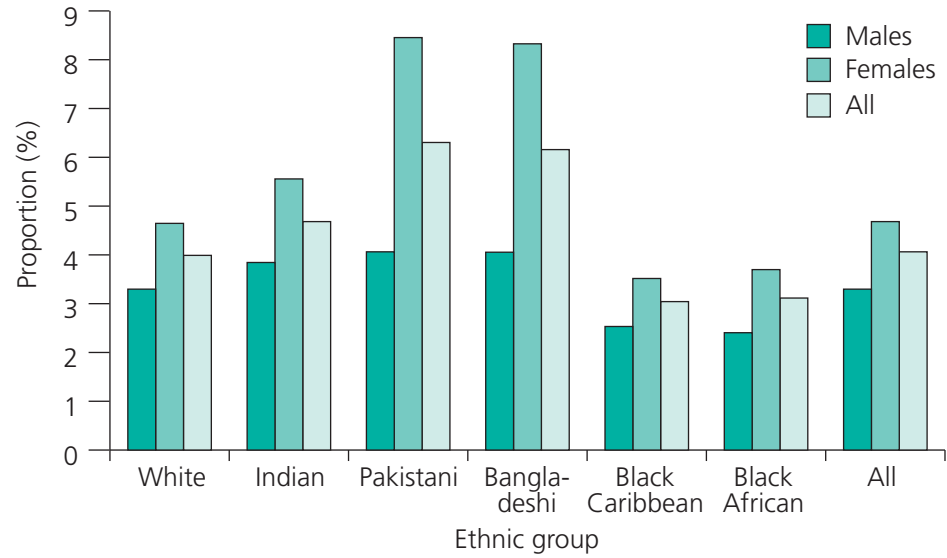
Source: *Census of Population and Housing in England and Wales 2001*, Office for National Statistics

Figure 2: Intensity of care among those providing care



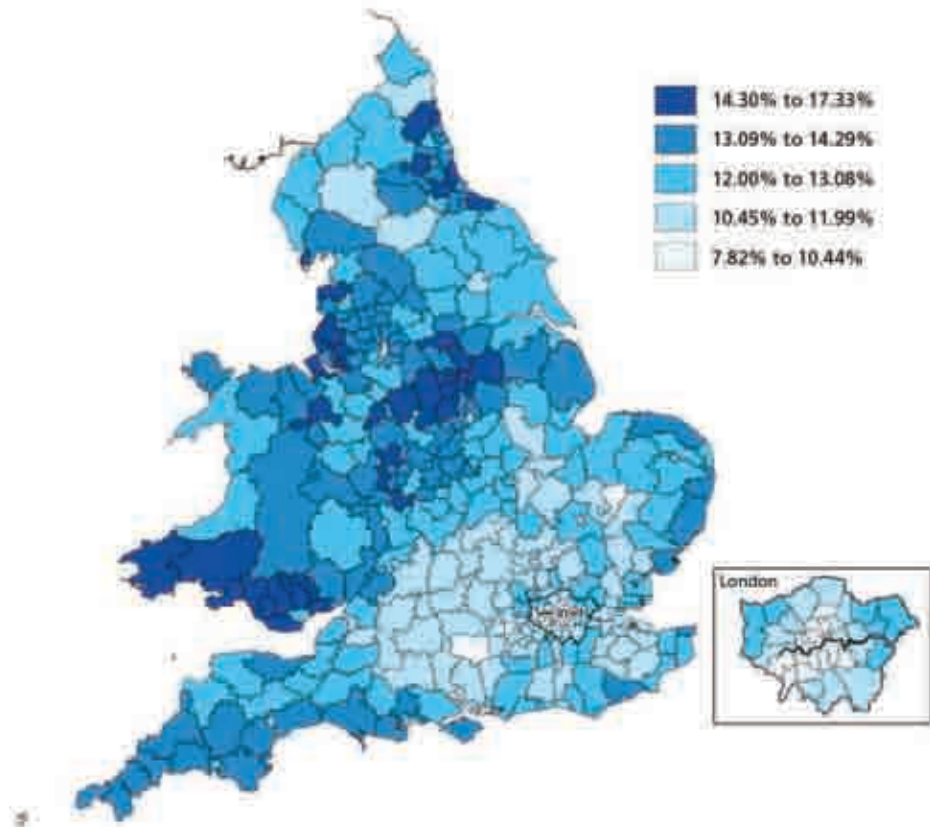
Source: *Census of Population and Housing in England and Wales 2001*, Office for National Statistics

Figure 3: Proportion of the population aged 16+ providing care for 20+ hours per week by ethnicity and gender



Source: *Census of Population and Housing in England and Wales 2001*, Office for National Statistics

Figure 4: Caring by geographic location



Source: *Census of Population and Housing in England and Wales 2001*, Office for National Statistics

The role of the family

- 1.14** The traditional source of care and support for those without full independence has historically been, and continues to be, the family. Families and friends value their caring roles and recognise the importance of mutual care and support within family relationships. Many carers and those they support talk of inter-dependence and mutual respect.
- 1.15** The best environment for the person being supported is very often their normal social environment – home. The aim of the strategy in focusing on personalised services is to support people and their carers in their own homes and communities wherever possible. This is a key aim of the wider personalisation agenda.
- 1.16** However, family life has changed over the last 50 or so years. The move to smaller nuclear families means that it is no longer as easy to share the caring role as widely as in the past. Society is more mobile and families are more geographically dispersed. More families rely on two incomes, or longer working hours, to maintain an adequate standard of living. Many families find it difficult to balance work with the care needs of friends and relatives without significantly impacting on their own standard of living, esteem and independence – the lifestyle to which the family has become accustomed.
- 1.17** The challenge we face is balancing the increase in the number of people needing care and the ready availability of those friends and family members able and willing to provide it. Facing up to the challenge is crucial, because the whole of our society depends to a large degree on the continuation of the care that carers provide. Society needs to encourage and help those many individuals who wish to help and support those they care for: our job is to create the right environment and systems that support those willing to take on caring responsibilities.

The role of government

- 1.18** The family is the cornerstone of much of the care and support we need, and will continue to need in the future. But we know from what carers tell us that many families need additional information, advice and support if they are going to undertake that role effectively. Importantly, they want recognition for the valued role that they play,

and personalised support both for themselves and for the person for whom they care.

1.19 The Government has a key role in improving the health and well-being of carers and those that they support. This is also true of the mainstream statutory services, including the NHS, Jobcentre Plus and local authorities. Local authorities have already signalled the high priority that they are giving to supporting carers through their Local Area Agreements (see Chapter 7). However, the statutory sector can only do this in partnership with carers themselves and those that they support. The Government should do those things that only government can, including:

- **Providing leadership** and establishing a framework to ensure that statutory services (for example those provided by the NHS and by local authorities) are of a good standard, designed to meet the carers' needs while at the same time enabling and encouraging local innovation to meet the diverse needs of local populations;
- **Monitoring the implementation** of the commitments set out in this strategy, and in particular the outcome of specific steps and initiatives, to ensure delivery of the overall vision and the five outcomes that it sets. Monitoring should ensure that the rhetoric of policy is reflected in real service changes on the ground that make a positive difference to individual carers and the people that they support;
- **Setting overall objectives** and agreeing key principles to enable local statutory agencies to design services that best meet the needs of local populations. This will lead to personalised services where the carer and the person that they support are in control. The era of central government designing and micro-managing services is behind us. Such approaches in the past were limited in terms of successful outcomes, risked perverse behaviour by those accountable for delivery and stifled innovation. Rather, we have a responsibility to ensure that all local agencies including Jobcentre Plus, local government and the NHS are enabled to provide or commission services specific to carers in their area, and that they have the support and framework needed to do this to maximum effect to achieve higher standards for all;

- **Helping to join up services**, ensuring that support for carers is not simply a job for one local agency, for example social services. All parts of the system, working with the third and private sectors at local level, must respond and play a part in service delivery in an integrated and seamless way. This way carers, and those that they support, are, as far as possible, unaware of the boundaries of individual agencies' responsibilities. This is little more than common sense, but the reality is that different specific areas of responsibilities have built up over the decades – often for sensible reasons – which can be difficult to join back together. It is our job to tackle these difficulties wherever possible and to ensure that joined-up service delivery becomes a reality. This is also the approach we take in the *Independent Living Strategy*, which emphasises the importance of joined-up services at all levels for disabled people.

The role of wider society

- 1.20** Wider society also has a part to play – largely one of recognition. It is important to recognise the vital role played by carers (both in providing large amounts of care and support and in saving the state a great deal of money) and the fact that society needs to support carers. The alternative, of providing all care through more formal arrangements, would result in a reduction of quality of care provided and impose an unsustainable financial burden on the state.
- 1.21** Recognition means that we want caring to be seen for what it is – invaluable support to individuals and to society as a whole. It means ensuring that those professionals who provide services for the person being cared for (for example health professionals, housing officials and those in the education system) should recognise that while the person being looked after is usually the expert in their own care, the carer too is a real expert. That being the case, carers should be consulted as partners in care and their unique knowledge and expertise recognised.
- 1.22** Employers also have a key role to play in recognising the valuable contribution that those with caring responsibilities can continue to make to the workplace and the economy. By acknowledging the specific needs of carers, employers can retain their experienced staff, and avoid the costs of recruiting and training new employees – as well as increasing employee loyalty. This has the added benefit of allowing carers to maintain their current and future income, and enabling a life outside of caring.

Role of the individual

- 1.23** The role of the individual is to recognise that caring for a family member, friend or partner is one of the responsibilities we all potentially face as part of family life. A key advantage to the provision of care by a family member, friend or partner is that such an approach can result in personalised, responsive, expert and high-quality care that is in the best interests of the person being supported.
- 1.24** But an expectation that family and friends will always be willing to support those they love when they need it must be accompanied by assistance and recognition from the state and wider community. In relation to children who are carers, there must also be recognition of the need to respect and protect their right to be children and to develop and move forward into adulthood with the opportunities and choices which others have.
- 1.25** Our shared vision for carers is one where the role of the individual is fully recognised and, where they need support in their caring role, carers will have choice and control over how that is delivered. The development of greater choice and control is one of the key ways in which we can improve the quality of care and support, and promote individual requirements for independence and dignity for both carers and the people they care for.
- 1.26** The following chapters of this strategy set out our commitments to ensure that the carer's role is recognised more widely and that carers receive increased support in the valuable role they undertake.

Chapter 2: Integrated and personalised services



Consultation: What carers have told us

- There is a lack of co-ordinated services centred on carers' needs. Carers are looking for greater personalisation of services enhanced by a greater cohesion between services;
- The current system frustrates and annoys carers. There is a need to streamline the process across the board;
- Many carers said that it was important for professionals to have a greater understanding about the role that carers have, and that we should ensure that carers' circumstances and needs are taken into account when they receive services.

Our vision is that:

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.

What this means

- 2.1** There will always be a need for care in this country. In fact, the forecast change in demographics will see the demand for care growing. In addition, people will always want to care for loved ones who need support.

FACTBOX

There will be a projected 1.6 million more adults in England with a care need by 2026 (a 30 per cent increase) and 2.9 million more by 2041 (50 per cent).¹²

- 2.2** We are committed to providing the services that carers need to carry out their caring duties. Services across the board, whether they be provided from central, local government or the third sector, must be fit for purpose in supporting carers. For this to happen, services must

¹² *Future Demand for Social Care, 2005 to 2041: Projections of demand for social care for older people in England*, PSSRU 2008; and *Future Demand for Social Care, 2005 to 2041: Projections of demand for social care and disability benefits for younger adults in England*, PSSRU, 2008

be sensitive to the needs of people from all sectors and groups within society, and must reflect local diversity within communities.

Carers in Armed Forces families

Lindsey is married to a soldier in the British Army. They have a 10-year-old child who is severely autistic. The family has moved four times in the last nine years, including two years spent in Germany, and have not lived close to any family member during that time. Lindsey's husband has been to Iraq, Afghanistan and the Balkans for six-month periods on four occasions since their child was born.

Although there is relocation support for Service families who are moving, inevitably it takes time to find out about and re-establish care provider services after each move. Similarly, without a well-developed network of family and friends, carers from the Service community can feel isolated and lacking in support.

For significant periods Lindsey is, in effect, a single parent with a disabled child. This adds pressure to any arrangements for Lindsey's work but also makes the need for breaks a more significant factor. During this time she needs to be supportive of her husband who can be involved in very demanding duties, maintain the family home and provide continuing care for their children while supporting them in any worries they may have with respect to their father. When her husband is not on operational deployments there can still be short notice and unpredictable events that disrupt planned arrangements for part of, or the whole, family.

CASE STUDY

CASE STUDY

Service providers need to be aware of the specific needs that carers like Lindsey who are in Armed Forces families have. Specific needs stem from:

- high mobility which puts a premium on good information and flexibility from service providers to ensure that families do not experience frequent, cumulative disruptions in the support they receive;
- relocations of the family which remove any network of support that had been established and trigger an increased need for service providers to offer support;
- periodic absences of one parent, sometimes for significant periods, which can mean the remaining carer needs additional or changed services and a supportive, understanding approach from service providers.

2.3 A key goal in our mission to improve support for carers must be to ensure that services are also improved for the people being supported. Carers have their own specific needs but very often their lives will be improved considerably if services are better tailored to the needs of the people for whom they care. We should not see the needs of carers in isolation from those of the people for whom they care. This echoes the wishes that carers expressed during the consultation.

“If the cared-for person’s needs are met through good day care, that is all I need to survive.” (Carer at a regional event)

2.4 The care and support services that a carer needs will vary from case to case, often depending on the care needs of the person being supported as well as other individual circumstances. It is highly likely that providing care and support will be the responsibility of a number of agencies from both the statutory and independent sectors. For example, health services will be involved in the healthcare needs of both the carer and the person they support, while the housing department may be involved where adaptations are needed to the home and social services involved for a range of other support services.

2.5 Carers (including former carers) may also be in contact with Jobcentre Plus on employment matters, with the Department for Work and Pensions for

benefits information, and with third sector organisations which provide a range of services to support carers. Systems need to join up in a more co-ordinated way around the needs of the carer and the person they support, empowering them both to live as full and active citizens.

- 2.6** The various agencies responsible for providing care and support should work effectively, together with the third sector, behind the scenes. The carer should not have to piece together support from many ‘suppliers’ who seem very often to be working against each other and against the carer. Delivery of our vision will be characterised by carers feeling that not only are services working together but they are “on their side”.

Regents House

Regents House in Nottingham acts as a safe haven for carers looking after people with substance misuse problems. Often these carers face the extra stress of stigma and worry over the criminality attached to substance misuse. Regents House was set up in 2000 by the Carers Federation (a Princess Royal Trust for Carers network member), with funding from both the Nottinghamshire County Drug and Alcohol Action Team and the Nottingham Crime and Drugs Partnership. Services include:

- drop-in support at Regents House;
- telephone support;
- outreach support – one-to-one support;
- group support – groups arranged geographically;
- specialist group support – a parents of young people group, a cannabis group and a bereavement group;
- a youth education programme, including support for drugs education in schools.¹³

CASE STUDY

- 2.7** In the past, the services on offer often seemed to be organised with the convenience of the provider in mind rather than that of the person in need of help and support, leaving carers with the view that they had to fight against the system. This should not be the case in the future. The move to greater personalisation across the public sector, and in particular in adult social care, should support this ambition.
- 2.8** We can achieve this vision and outcome by delivering greater integration between services, greater personalisation of services for carers and by empowering and enabling carers through better information and training.

“Professionals offer what is available – they don’t ask what I need. Nobody bothers to ask what would improve my quality of life.”
(Carer at a consultation event)

Integrated services

FACTBOX

Think Family – Improving the life chances of families at risk¹⁴

The Social Exclusion Task Force’s *Families at Risk Review* examined how systems and services can better meet the needs of families that face complex problems. It found that support for families is often poorly joined up and when families face many complicated problems, problems should not be addressed in isolation. The final report set out a vision of an integrated system that seeks to address this challenge.

The review advocates that services need to ensure that there is **no wrong door** to support. Support should be **tailored** to the family’s needs, build on the family’s **strengths** and address the **whole family**, not just individual members

www.cabinetoffice.gov.uk/social_exclusion_task_force/families_at_risk.aspx

14 *Think Family: Improving the Life Chances of Families at Risk*, Cabinet Office, 2008

2.9 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 (who have a specific right to an assessment) have their own individual assessment, to ensure that specific needs around their own health and well-being are identified. This approach will enable individuals and their carers to design care and support which better meets their individual needs and draws in contributions from a range of people, organisations, family and friends.

2.10 Such assessment will be supported by the development of a Common Assessment Framework (CAF) for adults, to share relevant information between agencies and encourage close working between councils, the NHS and other statutory agencies as well as the third sector.

2.11 The CAF for adults will seek to develop a shared data and information set on individuals, which will be accessible (with the appropriate consent) to a number of different professionals. The CAF will encourage self-assessment for carers and the people they support. It will ensure that this is placed at the heart of outcome-based assessments, in which the carer, the person they support and professionals work together on future care and support plans.

“You have to tell your story so many times.”(Carer at a consultation event)

*“Services should be joined up and require little effort from the carer to ensure that the information flows smoothly between departments. Bureaucracy should also be kept to a minimum.”
(Carer at a deliberative event)*

2.12 As the CAF for adults develops and is put in place, it is envisaged that carers will no longer have to go from professional to professional repeating the same information in the hope that someone can help them. Rather, it will encourage joined-up working between services through appropriate sharing of information, facilitating both self- and professional assessment, to ensure that the best possible support is given to carers in their caring role while respecting the wishes of the people they support.

2.13 The CAF for adults follows the introduction of the CAF for children in April 2006 to promote more effective, earlier identification of additional needs, particularly in universal services. The CAF for children

is intended to provide a simple process for a holistic assessment of a child's needs and strengths, taking account of the role of parents, carers and environmental factors on their development. Practitioners should therefore be better placed to agree with the child and family on what support is appropriate.

- 2.14** The CAF for adults will have another positive benefit for carers. It will be noted on their data set, and the set of the people they care for, that they are the carer. GPs, nurses and care workers will be aware that carers are involved and should start to include them, where appropriate, in the care planning procedures and in future decision-making.

FACTBOX

Fair Access to Care Services

Fair Access to Care Services (FACS) provides a framework for councils setting their eligibility criteria for adult social care. Introduced in 2003, its aim was to ensure fairer and more consistent eligibility decisions across the country.

A report this year by the Commission for Social Care Inspection (CSCI), *The State of Social Care in England 2006–07*¹⁵, looked at the outcomes for people using services and carers who do not meet local eligibility criteria; it found that people often struggle and experience a poor quality of life. CSCI also found little consistency, both within and between councils, as to who is eligible for services.

A review of FACS is being undertaken by CSCI, who will report to the Care Services Minister in September 2008.

Current FACS guidance makes it clear that carers should be involved in assessments and subsequent decisions about the help that is provided to the person they support, and that their own needs should be assessed where the focus is on the carer's needs and the sustainability of their caring role.

The CSCI report can be downloaded from www.csci.org.uk/about_us/publications/state_of_social_care_07.aspx

Health and social care

2.15 Carers have often been seen as a social care issue alone and it has sometimes been difficult to engage the NHS in providing them with support. The need for more integrated working between the NHS, social services and carers is an issue that came across strongly during the consultation.

“We need more partnership involvement with health professionals with regard to the care of the people we support.”
(Carer at a consultation event)

2.16 We have recognised that there need to be greater moves across government to encourage more effective co-operation between statutory bodies at a national, regional and local level to provide better services for the public. Nowhere is this more important than in relation to carers.

2.17 We have signalled our intent to do this in *Putting People First*. The Operating Framework for the NHS 2008/09, which sets out the specific business and financial arrangements for the NHS in any given year, has made specific references to supporting carers **for the first time**¹⁶ (see Chapter 5).

2.18 The Next Stage Review of the NHS, led by Lord Darzi, will publish its final report in summer 2008 and will look at the future arrangements for the delivery of high-quality healthcare for the whole population. Each strategic health authority (SHA) has published their future vision which sets out the shape of regional healthcare for the next decade.

¹⁶ *The NHS in England: The Operating Framework for the NHS in England 2008/09*, Department of Health, 2007

South West SHA

The vision set out by the South West SHA contains a number of references to involving and supporting carers in the future. In particular it sets the following ambitions:

- for people with long-term conditions – increase by 5 per cent per annum the percentage of carers of people with a long-term condition who have a carer assessment and support;
- for people’s mental health – improved access and support for carers: assessments and care plans completed within four weeks of a newly referred service user assessment by 31 March 2010.

CASE STUDY

2.19 New commitment: To support this move in the NHS and to encourage partnership working between the health, social care and third sectors, we are making a commitment over the next three years to run pilots looking at ways in which primary care trusts (PCTs) can better support carers. The sites will gather evidence of the benefits to both carers and the NHS of better service provision and interaction for and with carers in hospitals, GP surgeries and other arenas.

2.20 The pilots will seek to enshrine good practice such as:

- actively involving carers in diagnosis, care and discharge planning;
- providing greater support for carers at GP practices and acute trusts;
- working in partnership with local authorities and the third sector to provide flexible support for carers.

Torbay Care Trust

Torbay NHS Care Trust is responsible for integrated community health and adult social care. It has a lead officer for carers' services, a senior post jointly funded by the local authority and the PCT since 2002, who leads on the local inter-agency carers' strategy 'Measure Up'.

The ambitions for local carers' services are embedded within Torbay's Joint Strategic Needs Assessment (JSNA). These are linked to a three-year action planning cycle to ensure continued development and improvement as part of the Local Area Agreement (LAA). There is a target to identify more carers given the older profile of the population. (See Chapter 7 for further details on JSNAs and LAAs.)

Strong partnership arrangements, together with a shared "can do" ethos and an outcome-focused approach, underpin the carers' services. The welfare of carers is also a priority at board level within the organisation, with a non-executive director having a lead for carers and an annual programme of carer shadowing in place.

Carers support workers are attached to all GPs surgeries, providing emotional and practical support for carers identified through primary care. These posts have established trust and confidence in primary care, and provide continuity and an accessible service to carers (who do not have to meet any eligibility criteria). The carers support worker role has also raised awareness among primary healthcare staff in GP practices.

The Trust is hoping in the near future to explore the benefits that a carers centre could bring to the area.

CASE STUDY

FACTBOX

National Stroke Strategy

The new National Stroke Strategy¹⁷ was published in December 2007. It presents a challenging programme to improve stroke treatment, care and support over the next 10 years.

The strategy sets out 20 quality markers for the provision of high-quality treatment and care for adult stroke survivors. Seven of those quality markers link directly to the kind of support and services that those who have had a stroke and their carers need in the community; these include high-quality rehabilitation, information, advice, and practical and peer support throughout the care pathway, in line with individual need.

The strategy can be downloaded from: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081062

The third sector

- 2.21** Many carers prefer to deal with third sector organisations than with the statutory services for a variety of reasons; these include their independence, the opportunity for peer support and their diversity of supply, which meets the wide range of carers' needs. We recognise the vital role that these organisations play in ensuring that carers have the greatest possible flexibility in receiving and accessing support and services, and we will continue to work with them and encourage the commissioning of services from them.
- 2.22** Support for the third sector comes from both central and local government, and in a number of local authorities almost all of the Carers Grant is routed through third sector organisations.
- 2.23** Third sector organisations play a valuable advocacy role in supporting carers to influence the design and delivery of mainstream services and support. This role is crucial in the wider reform agenda to ensure that carers' voices are heard at the centre of commissioning decisions.

17 National Stroke Strategy, Department of Health, 2007

2.24 However, stakeholder groups have identified that the services offered by third sector organisations vary from region to region, and their reach is not as great as they would want.

Sefton Carers Centre

Sefton Carers Centre and Sefton Metropolitan Borough Council have a long-established and effective partnership which has had a significant impact on improving the lives of carers in Sefton.

A broad menu of services is available through the centre including a bi-monthly newsletter, an information service, holistic therapies, counselling, training and education, social events and welfare benefits advice.

The centre employs a number of carer support and advocacy caseworkers who help carers access services for the people they care for, and who address carers' emotional needs through various means such as facilitating support groups and providing a listening ear.

Staff from the council have been seconded to the centre, which has been commissioned by the council to carry out a number of services (such as delivering Sefton's carers' vouchers scheme) on its behalf.

CASE STUDY

2.25 New commitment: In recognition of the vital role that third sector organisations play in supporting carers, and the trust they have among carers, we are committing funding over the next three years to build capacity in the sector at both a national and a local level.

2.26 We will continue to work with local government and the third sector to ensure that the services it provides have far greater reach, and that it is able to play a greater role in every local authority area in working with councils and PCTs to deliver the best possible support for carers.

Workforce

- 2.27** The workforce in a range of agencies, including those in health, housing, benefits and employment services, is absolutely vital in delivering the vision set out in this strategy and ensuring that the commitments we have made are implemented with the greatest possible impact.
- 2.28** Carers and stakeholder groups have both called for improvement in the workforce that supports both carers and the person they care for. This is closely tied in with the aim of improving the service provision for the person being cared for in order to improve the life of the carer.
- 2.29** Furthermore, the workforce needs to give carers the recognition they deserve through treating them as expert partners in care. There are also issues about the quality and suitability of the replacement care being offered to carers. If carers are to be able to take a break and combine paid employment with caring, they must have confidence in the quality and competence of those that will be replacing them. The workforce also needs to reflect the diversity of those needing care. Language and cultural barriers between care workers and those they care for can have a detrimental effect on the quality of support offered. Enabling the workforce to better support the carer and person they support is key to the success of this strategy.

Ten Key Words Toolkit

Research highlights how BME users and carers feel more valued and respected when staff learn a few key words of their preferred language. This toolkit, developed by Hertfordshire County Council, shows staff how to say key phrases/words in various languages.

www.hertsdirect.org/caresupport/carersupport/supportadcarers/bmec/

CASE STUDY

- 2.30** The social care workforce is absolutely vital in enabling and achieving the social care transformation agenda set out in this document and many others. The adult social care workforce strategy will set out the implications of *Putting People First* for the workforce.
- 2.31** There is a particular focus on the workforce's involving carers as experts and partners in care, in addition to putting carers together with service users at the centre of service provision.
- 2.32** Furthermore, the workforce strategy is investing over £130 million in the development of the adult social care workforce to take account of the goals that it sets. A major part of the workforce's role is to support self care which relates to the core principles described below.
- 2.33** We have recently announced our seven 'Common Core Principles¹⁸ to Support Self Care' which are designed to give people control over their lives so that they, their families and their carers can maintain and improve their well-being and independence. This is a major step towards ensuring that the workforce in both health and social care can meet the needs of both the person supported and their carer.



FACTBOX

The Common Core Principles to Support Self Care are:

- ensure individuals are able to make informed choices to manage their care needs;
- communicate effectively to enable individuals to assess their needs, and develop and gain confidence to self care;
- support and enable individuals to access appropriate information to manage their self care needs;
- support and enable individuals to develop skills in self care;
- support and enable individuals to use technology to support self care;
- advise individuals how to access support networks and participate in the planning, development and evaluation of services;
- support and enable risk management and risk taking to maximise independence and choice.

2.34 Carers told us during the consultation that they often cannot access the services that they want or often do not receive the support they need from the range of agencies that should be concerned with providing services related to health, social care, benefits, housing, leisure and many other areas.

2.35 A greater awareness of carers and the particular issues that they face is needed not only by health and social care professionals but also by professionals working across the piece. They need training so that they can provide the information and services that carers need to support them in their caring role.

2.36 New commitment: To this effect, we are investing in training a range of professionals in local authorities to support carers more effectively in their day-to-day dealings with them and when making commissioning decisions at a local level. The training will also bring professionals together in their local area, facilitating more joined-up service provision on a micro level providing major benefits to carers.

Listening to Carers DVD

The four supporting carers beacon authorities (in Hertfordshire, Rochdale, Sefton and Sunderland), in partnership with Carers UK and the Social Care Institute for Excellence, have made a DVD to support the training of staff in carrying out effective carers' assessments. The DVD features carers talking about their experiences of the assessment process, and an accompanying training pack has been made by Carers UK and other partners. For the DVD and training pack, visit www.listeningtocarers.public-i.tv

CASE STUDY

Support for those caring for children and young people

- 2.37** Families with disabled children have particular needs for information. The Early Support programme, covering all disabled children below the age of five, promotes wraparound, timely provision for young disabled children and their families. It provides parent carers of disabled children with condition-specific information and enables them to gain knowledge about other important areas such as education and financial help.

FACTBOX

Early Support

Early Support is the Government programme for achieving better co-ordinated, family-focused services for young disabled children and their families. It promotes the development of integrated services which function with carers as partners.

The programme works through a set of standard materials shared by carers with anyone providing treatment, therapy or practical help for their child. The materials can be used flexibly in many different circumstances to ensure that all those in contact with the family work as a team. They provide:

- standard information on how the system works and about particular conditions like Down's Syndrome;
- a joint planning process which puts families at the heart of discussion and decision-making about their child through a Family Service Plan;
- an audit tool to help those with strategic planning responsibility plan for change.

Early Support also provides carers with an Early Support Family Pack and a Family File to encourage partnership. The Family File helps families to:

- navigate their way around the system;
- co-ordinate appointments and service provision;
- share information about their child so that they don't keep having to say the same things.

Printed and online versions of the programme materials are available. Background information and practical guidance on using the programme and the associated training programme can be found at www.earlysupport.org.uk.

- 2.38** The transition of young people from children's services to adult care can be a difficult time, both for them and for their carers. This is because they often face an uncertain future, not knowing whether services will continue to be provided or who will be providing them.

2.39 The 2007 report *Aiming high for disabled children*¹⁹ (see box below) recognised the need for better transition planning and support, and we are investing £19 million between 2008–2011 to initiate and develop a transition support programme. This will be based on transparency, co-ordination and support for parents and carers, children and professionals.

FACTBOX

Aiming high for disabled children

In May 2007 the then Department for Education and Skills and HM Treasury published a report, *Aiming high for disabled children: Better support for families*. Based on a review of local services, it built on the Every Child Matters programme with commitments to specific action in three priority areas: access and empowerment; responsive services and timely support; and improving quality and capacity.

Key to this programme is the core offer which families with disabled children can expect across the country from local services. The core offer principles are information; transparency; assessment; participation; and feedback.

The report also committed us to developing a Transition Support Programme aimed at enabling and supporting young people with disabilities to move seamlessly into a new stage of life. The focus will be on:

- good-quality information regarding options and choices available to them and their families;
- involvement in their transition progress, making the young person the centre of a positive discussion so that they and their family can have a say about what they enjoy, within and outside school, and what they would like to do in the future;
- effective multi-agency working to support the young person;
- a focus on those with the most complex needs and what that means as they move into adulthood.

The full report can be viewed at www.hm-treasury.gov.uk/media/C/2/cyp_disabledchildren180507.pdf

¹⁹ *Aiming high for disabled children: better support for families*, Her Majesty's Treasury and Department for Education and Skills, 2007

2.40 Furthermore, we are already providing funding under the ‘Parents know how’ programme for Contact a Family, a charity for families with disabled children, to provide a helpline specifically for parent carers to support them in their caring role.

Personalised services

2.41 Much has been done recently to move away from a model that seems to be designed around the needs of services, which many will recognise, to a far more person-centred way of delivering support. *Putting People First*, which is set out in its entirety at Annex A, sets out our vision for the transformation of adult social care to a more personalised system.

2.42 *Putting People First* signals the commitment across central and local government, the NHS and other sector leaders to work together to support individuals and their carers.

FACTBOX

Valuing People Now

Personalisation is a key priority for people with learning disabilities and their families, for example, as set out the *Valuing People Now* consultation document.²⁰ This paper builds upon the *Valuing People* White Paper²¹ which set out the Government’s aim to achieve equality of citizenship for people with learning disabilities. *Valuing People Now* sets out the next steps for the policy and its delivery. The main priorities for the next three years are personalisation, what people do during the day, better health, and improving people’s housing. Families are important long-term partners in making change happen, and family carers have a right to a life of their own.

2.43 Personalisation can be summarised as ‘the way in which services are tailored to the needs and preferences of citizens, with the overall aim being that the state should empower citizens to shape their own lives

20 *Valuing people now: from progress to transformation – a consultation on the next three years of learning disability policy*, Department of Health, 2007

21 *Valuing People – A New Strategy for Learning Disability for the 21st Century*, Department of Health, 2001

and the services they receive'. It means that services can be more sensitive to the age, faith, ethnicity, gender and sexual orientation of the people who use them, and can be designed to meet the issues which are most important to those people.

- 2.44** This new approach shifts the balance away from just professionals making decisions to a recognition that people should be active citizens rather than passive recipients of support.

Sign Up

The Sign Up project in Oxfordshire supports carers and families of deaf children and young people. Severe communication problems can often lead to poor behaviour and inappropriate coping strategies, so tutors visit homes to teach the whole family basic methods of communication, such as British Sign Language.

As a result, carers have reported less stress within the family as communications become easier. Siblings and grandparents have engaged with great enthusiasm, and carers have commented on improvements in the emotional health of their children. Early referral means that improved communications within the family start sooner, thus reducing the risk of emotional or behavioural problems.

CASE STUDY

Personal budgets

- 2.45** Direct payments, cash in lieu of social services, help to deliver personalised care and support. Local authorities must offer direct payments to people who are eligible for community care services. They can benefit carers by giving them and the people they care for the flexibility to purchase services that are tailored around both their needs rather than having to fit into a programme of services offered by a local authority. We would like more service users and carers to feel that they are able to take advantage of the benefits that direct payments can bring.

Direct payments

Ashok is a Hindu service user who only speaks Gujarati. Prior to receiving direct payments he had been receiving help with personal care from a home care agency.

The service was unsatisfactory, with missed and late visits making it difficult for Ashok to plan ahead. Furthermore, the language barrier meant that his family needed to take up concerns on his behalf as nobody from the agency was able to understand him.

The unreliable service meant that Ashok's family found it hard to get a break. Although they raised these concerns with the homecare agency, nothing was done.

Using his direct payment, Ashok now employs someone from his local community (who speaks Gujarati) as well as a woman who was recommended to him by a family member; she too has learnt some key words in Gujarati to help communication.

Guidance on requesting and receiving direct payments is available at www.direct.gov.uk/en/CaringForSomeone/MoneyMatters/DG_10018517

CASE STUDY

- 2.46** Parliament is currently considering legislation to extend the availability of direct payments to people who lack capacity under the Mental Capacity Act 2005; it is envisaged that this legislation will come into force in spring 2009. This will provide major benefits to carers by allowing them greater flexibility, in terms of being able to receive direct payments instead of local authority services, on behalf of people who lack capacity. The changes will be of particular benefit to parents of severely disabled children, who currently lose their direct payment when they turn 18, and are likely to be of benefit to those caring for relatives with dementia or who have had severe head injuries.

2.47 We recognise, however, that direct payments are not the solution for everyone. For that reason, *Putting People First* has signalled that councils will move in the next three years to a position where everyone in receipt of social care funding will have a transparent, up-front allocation of the funds available for their care and support – a personal budget. This is dealt with in greater detail in Chapter 3.

FACTBOX

Personal budgets

A personal budget is a term used to describe an up-front, transparent allocation of social care resources to individuals. It could be managed by a council or another organisation on behalf of an individual, be paid as a cash sum (a direct payment) to the individual, or be a mixture of both – it is for the individual to choose.

2.48 The use of personal budgets, and the focus on improving outcomes for both the person needing care and support and the carer, will encourage a change in culture and mindset. Personal budgets allow for better outcomes as the person being supported and the carer have choice and control over what services – such as the provision of breaks – best meet their needs. *Putting People First* recognises that people will need improved advice, advocacy and, where appropriate, support in managing their personal budgets. It is also important that councils consider appropriate solutions to managing risk with individuals, carers and their families.

2.49 This outcome-based approach to service provision sets the direction of travel not just in social care but also across government, and recognises the mutual relationship between the carer and the person they support.

2.50 In the longer-term, we will consider extending flexibility in the way personal budgets and direct payments can be used.

- 2.51** We have also piloted individual budgets in 13 local authorities in 2006/07. Individual budgets bring together a number of income streams from different agencies to see whether providing greater flexibility delivers benefits to the recipients and enables them to look more holistically at their needs and the needs of their carers.
- 2.52** The evaluation of the pilots is due to be published later in 2008 with a specific evaluation being undertaken around individual budgets and carers.
- 2.53** These mechanisms also have a number of benefits for carers in terms of allowing them to take breaks from their caring role. These topics are dealt with in Chapter 3.

Crossroads North East

Crossroads North East has a new scheme supporting carers who receive direct payments and individual budgets, as well as people funding their own care, to select and employ staff to provide meaningful respite care in and around the home, without the potential stress that can come with being an employer.

The scheme aims to take the hard work out of employing dedicated personal assistants, by recruiting them itself and then training them if necessary. People who use the service, which includes ongoing monitoring, will be expected to pay for it, but they will get value for money as the burden of stress on the carer is reduced.

CASE STUDY

Empowering and enabling carers

Information

- 2.54** *Caring about Carers* recognised the importance of information for carers. Easy access to comprehensive and up-to-date information at the right time continues to be fundamental in supporting carers, and was highlighted during the consultation.

“Better information about service provision is a key priority for improving the lives of carers. Carers need easily accessible, digestible information which is tailored to their needs.”

(Carer at a consultation event)

- 2.55** Assisting carers in their caring role by meeting their need for information reflects one of the central tenets of the personalisation agenda. *Putting People First* states that one of the components of a personalised system of adult social care is a “universal information, advice and advocacy service for people needing services and their carers”.
- 2.56** Information for carers needs to be available in a variety of media and formats so that it is accessible to all, including those with learning disabilities or limited English. At present, unfortunately, fragmented information is disseminated by a number of agencies, often leaving the carer wondering where to begin.
- 2.57 Commitment:** To meet this need, a key component of the New Deal for Carers is the provision of an information service. This will provide, via a website and a single national telephone number, easy access to the comprehensive range of information needed by carers. Carers will be helped by the service directly and through signposting to other services that are more appropriate to meet their needs. We are making available £2.775 million per year to fund the service.
- 2.58** The service will support carers of all ages, and will ensure that the needs of those who have traditionally had disproportionately less support than carers as a whole or who may be more isolated in the community – receive greater focus.
- 2.59** The helpline and website will be in place by spring 2009. The service will work with other similar services to maximise the value of information services for carers. In *Lifetime Homes, Lifetime Neighbourhoods*²² we announced that we would also develop appropriate national housing advice and information, working with providers and building on what already exists. We will ensure, as part of the scope of the information service, that full consideration is given to potential integration with and links between key helplines and websites to ensure easy navigation for those using these services.

22 *Lifetime Homes, Lifetime Neighbourhoods: A national strategy for housing in an ageing society*, Communities and Local Government, 2008

- 2.60** Although the helpline and website, together with *Putting People First*, will make significant strides towards the comprehensive provision of information for carers, there is still more that can be done to ensure that all carers have information relating to their locality and their particular circumstances.

Somerset County Council

According to the 2001 Census, there are around 53,000 carers in Somerset, but only about 6,500 of them access Somerset County Council's services and support.

The council is aiming to make access to services and information possible at a neighbourhood level through Somerset's village shops and post offices.

Initially, staff from 20 shops will attend a carers information seminar explaining the information and services available, and will be given information about Somerset Direct – the access point for this information. By using the personal relationships that exist locally between the shopkeepers and their customers, it is hoped that information for carers will be shared at a local level. The 20 shops will also be supplied with carers information leaflets and posters.

CASE STUDY

- 2.61** In addition to a national source of advice, carers have clearly identified a need for personalised, targeted information which will reduce some of the difficulties that they face. There is a danger of 'information overload' if a carer is bombarded with a generic pack of information, only a small part of which is relevant to them.

- 2.62 New commitment:** So, to enhance the service offered by the new advice line and information provision for carers as a whole, we are committing funding over the next two years to help ensure the provision of information is comprehensive, easy to access (by being available in a variety of languages, for example) and up to date about services available in each carer's local area.

Carers' training

2.63 Carers often come into their role unexpectedly and have to take on a range of responsibilities for which they may not be adequately prepared. While carers selflessly take on their role, they often struggle with the vital responsibilities they have assumed and lack the skills they need.

2.64 Commitment: In recognition of this, we are establishing Caring with Confidence, a training programme for carers. This will build on existing training, empowering and enabling carers to enhance their own well-being and that of the people they care for.

2.65 The published objectives of Caring with Confidence are:

- work in partnership with the person they care for, and with social care and health professionals;
- safeguard their well-being and health, and that of the person they care for;
- undertake the practical tasks associated with their caring role as safely and effectively as possible;
- access and make appropriate use of services and benefits available to support them, and the person they care for;
- manage the emotional impact of their caring role;
- be better equipped to create and maintain new life roles as a carer and beyond;
- advocate effectively – on their own behalf, or on behalf of the person they care for;
- move from a position of dependence to self-direction as citizens;
- provide vital training for carers in terms of their day-to-day caring role;
- provide recognition of carers and their caring role;
- empower carers in their dealings, particularly with health and social care professionals;
- ensure that carers are helped to provide the most effective care for the people they are supporting.

- 2.66** Caring with confidence will be available to all adult carers, but will be targeted toward those carers who have, to date, received proportionally less support than carers generally, or who may be more isolated in the community.
- 2.67** The training will be available on a face-to-face basis from August 2008, and on a distance learning basis from December 2008. We are making £4.6 million available per year to fund the programme.

Longer-term measures

- 2.68** It is important that, during the life of this strategy, we continue to increase the service provision for carers. With a continued move towards more localised and tailored services, we must ensure that carers are able to access services that meet their specific needs.
- 2.69** We will explore possibilities around enabling all carers, no matter where they live, to access specialist carers' services which can support them in a way that suits them.
- 2.70** In the vast majority of cases, such provision already exists. However, we are committed to ensuring more comprehensive coverage to meet the needs of every carer in the country, and we will explore possibilities in the longer term to ensure that this happens.
- 2.71** *Putting People First* signals the intent to strengthen advocacy and support services in order to help individuals and their carers navigate through services. In many cases, this role has already been taken on by health and social care professionals, but we want to ensure that everybody can benefit from support that meets their needs.
- 2.72** Where appropriate, we will consider offering carers, with significant needs, a lead professional to help carers access services and to ensure early intervention when circumstances change.

Short term: Commitments

Training and awareness raising for key professionals.

A carers' information helpline and website.

Funding for accessible information provision about the local area for carers.

Caring with Confidence, a training programme for carers.

Pilots to look at how the NHS can better support carers in their caring role through developing models of best practice and enabling more joined-up service provision between the NHS, local authorities and the third sector.

Improvements to the capacity and reach of third sector services at national and local levels.

Longer term: Identified priorities

Carers' being able to access specialist carers' services in every community.

Consider extending flexibility of the way personal budgets and direct payments can be used.

Where appropriate, the offer of a lead professional to help carers access services and to ensure early intervention when circumstances change.

Dissemination of models of best practice to PCTs on how to provide better support for carers.

Chapter 3: A life of their own



Consultation: What carers have told us

“When a person becomes a carer they give up many of the opportunities that non-carers take for granted. Carers’ lives also become increasingly synonymous with the person they care for, which limits the opportunities they have for a life outside their caring role.”

At the deliberative events, provision of breaks and replacement care were deemed the highest priority by carers when examining the proposals of both the Health and Social Care Task Force and the Employment Task Force.

“On the occasions I get respite cover it’s great. If you get the right person in, you can relax and focus on yourself and your own well-being for a short while.”

“Planned breaks would make a huge difference to full-time carers. But you would need to be confident that the quality of respite care is good.”

Our vision is that:

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

What this means

- 3.1** 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.
- 3.2** There are a number of interventions or initiatives that can help the vision become a reality. *Putting People First* sets out the framework for providing everyone, including carers, with considerable improvements in terms of choice and control over key matters relating to their own lives and the lives of those they support.
- 3.3** In giving carers a life outside caring, we believe there should be a 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.

- 3.4** Services must not only support carers in their caring roles but also seek to improve the carers' quality of life and support the ambition to give them a life outside caring. *The case for change – Why England needs a new care and support system* states:

“The Government wants a society where all are respected and included as equal citizens and where everyone has the opportunity to fulfil their potential.”

- 3.5** The carers' strategy has a major role in ensuring that this vision is fulfilled, and work in four key areas will drive this forward: break provision; personalisation; improvements in technology; and housing, leisure and transport.

Break provision

- 3.6** The Department for Children, Schools and Families recently announced £370 million to be provided over three years to improve the provision of short breaks for families with disabled children. This is in direct response to evidence collected for *Aiming high for disabled children*, which found that short breaks are seen as the highest-priority service for families with disabled children.
- 3.7** Twenty-one pathfinder sites will initially lead the work to provide many more disabled children with enjoyable and valuable experiences away from their parents and carers. This in turn will give parents and carers the opportunity to take a break from their caring responsibilities.
- 3.8** In some cases, enabling carers to have a life outside caring is more about changing their daily routine to give them an opportunity to meet new people, some of whom have shared experiences, than it is about having a break from the people they support. A number of third sector organisations offer meals out, drop-in centres and similar schemes where this happens. Support for the third sector to increase the availability and reach of such schemes is set out in Chapter 2.

Richmond Carers' Café

Richmond upon Thames Crossroads, with support from the Alzheimer's Society, the Big Lottery Fund and others, provides carers and people affected by dementia with the opportunity to socialise in a friendly and welcoming environment supported by skilled staff.

The café is open every Saturday from 11am to 4pm in the centre of Richmond on premises given free by Richmond Age Concern, and provides respite, support, social opportunities and activities to tackle isolation. Transport is provided when needed.

Up to 10 people with dementia can use the café while their carers go into town for up to two hours, but most carers wish to remain with the person they care for. Workers including a part-time co-ordinator, four café support workers, a receptionist and a dementia advice worker, together with volunteers, receive training in subjects including dementia care, personal care, and moving and handling.

CASE STUDY

- 3.9** The consultation provided clear evidence of the importance that carers attach to breaks. Although major progress has been made over the last decade, we recognise that there is a demand for more breaks than are currently provided.

"[Planned breaks] are a good idea, it will cost money but it is important, it will help the carer and could prevent higher costs in the long run as giving carers breaks would prevent the carer becoming ill."

(Carer at a consultation event)

- 3.10** There is no doubt that consistent, high-level caring can feel relentless if there is no prospect of a break for carers from time to time. By preventing the breakdown of the valuable support that carers provide, not only is the financial cost of repairing carers' own health

avoided, but the additional cost of providing alternative care for the people they are supporting is avoided too.

Headway Oxford Breaks for Carers

Headway in Oxford supports adults with acquired brain injury, their carers and their families. It is a specialist service which also offers short breaks for carers, often at comfortable hotels in various parts of the country. Alternatively it can provide a break away for the cared-for person, to allow the carer a break at home.

Some brain-injured people suffer high levels of anxiety if separated from their carers overnight, so for these carers to have peace of mind it is essential that they accompany the people they support on the break. These breaks offer mutual support for carers; brain injury is an often misunderstood condition, and carers of people who are brain-injured are not used to meeting others who understand their particular problems. Friendships formed during these breaks can help during the rest of the year.

CASE STUDY

3.11 New commitment: In response to the high value placed upon breaks by carers, we are investing £150 million over the next two years. This extra funding recognises the value of carers in today's society and their ever-growing importance in the future.

3.12 The money will be allocated to PCTs, who will be required to work with their local authority partners to publish joint plans – as part of the Joint Strategic Needs Assessment process (see Chapter 7) – for the provision of breaks. These plans will be published following a local consultation with relevant parties, including the third sector and carers themselves. Setting out a strategy for improving quality and choice, the plans will take account of both the new money and the existing money provided to local authorities for planned breaks through the Carers Grant.

- 3.13** The Operating Framework for the NHS due to be published in autumn 2008 will set out how PCTs can work with local authorities to deliver short breaks for carers in a personalised way.
- 3.14** This additional funding significantly increases our investment in direct support for carers, and we expect that it will provide a wide range of services in response to their specific needs – from holidays with the people they support through to sitting or befriending services or access to local leisure services. It gives a clear indication of our commitment to ensuring that carers are able to have a life outside caring.
- 3.15** Although carers tell us how much they value breaks, there are still major gaps in the evidence as to the best and most cost-effective ways to provide them.
- 3.16** **New commitment:** To ensure that these gaps are filled, we are committed to running a set of pilots over three years in local authorities. These will:
- encourage and collate innovative approaches to break provision;
 - examine the quality of break provision;
 - look at the cost-effectiveness of breaks;
 - look at how personal budgets can be used to provide breaks for carers;
 - provide models of best practice to disseminate across local authorities and PCTs.
- 3.17** In the longer-term, in the context of community empowerment and the reform of the care and support system, we will 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.

Personalisation

- 3.18** *Putting People First* sets out the principles underpinning the sector-wide commitment to transforming services for individuals and those family members and friends who support them. Personal budgets signal the

move towards a system where person-centred planning is at the heart of the services provided by central and local government, and services are tailored to meet the needs of individuals and families.

- 3.19** Personal budgets have already been considered in the context of service provision (see Chapter 2) but they are equally important as mechanisms to enable individuals to have a life of their own. For example, personal budgets will offer the carer and the person being supported more choice and flexibility in the services that they purchase to meet their needs. Provided that they are tailored to meeting agreed outcomes for the carer or the person cared for, they can be used in a flexible and creative way to deliver the right sort of support.
- 3.20** They can be used, for example, to provide practical support for the carer in activities (such as window cleaning or gardening) that are important to the carer but are hard to manage, or to bring in extra support. It will mean that services can be designed to reflect the particular needs of carers and the people they support, and will continue the move away from the “one size fits all” model.
- 3.21** Over the next few years, we are committed to giving every person using social services, including carers, a personal budget. Personal budgets will enable carers to live a life outside their caring role while still ensuring that the people they care for receive the high-quality support they need.

Individual budgets

Chris cares for her parents who are in their 80s. They were struggling to cope with the irregular service provision from the local council, so Chris asked if they could have an individual budget to develop a package that suited their needs and lifestyle better.

Chris's mother now has a personal assistant (PA) who visits at a time that suits her, and she is able to have a bath every day rather than once a week. The PA provides help with ironing and other household tasks, and takes Chris's mother to the day centre so that Chris does not have to wait for the bus with her mother.

Chris also arranged for her parents to take a respite break together in a small hotel in Bournemouth, rather than her mother going into residential care. A local agency visited her parents to provide support, and friends of the family took them there and brought them back in return for a good meal out.

Importantly, Chris's father also has a male PA who visits once a week, goes on a walk with him and does small DIY jobs that he is unable to do since the loss of his sight. For Chris, individual budgets mean that she has people to help her parents when things go wrong – this is great as she works full-time.

CASE STUDY

3.22 Technology can play a major part in giving carers peace of mind, and in doing so can provide space that they can call their own. One of the recent innovative solutions to enable independent living is Telecare. This involves a range of technologies such as sensors placed around the house which are triggered by unusual activity such as opening the front door at night or leaving the gas on and unlit; triggering a sensor which sends an emergency call through to a monitoring centre.

3.23 Telecare provides carers with peace of mind and a degree of freedom based on the knowledge that the people being cared for still have support in place if they are not there. It can also allow carers to go about their daily activities: shopping, hanging out the washing or simply spending a bit of time on their own or with friends, which can be so important.

Telecare

Barbara is in her 80s, has moderate dementia and lives alone. She had been leaving her home during the night, and her family had been keeping a close watch on her and escorting her home on occasions. This was causing a great deal of stress for the family. A telecare package was installed, including a 'property exit sensor' which sent an alert to a 24-hour 'careline' telephone service. The operators managed to talk to Barbara and persuade her to come back into her house 87 times in a three-month period. Only on three occasions were the family called out.

CASE STUDY

3.24 It is important that we continue to invest in technology to improve the support offered to both the person cared for and their carer. We have made available £80 million to local authorities through the preventative technology grant between 2006 and 2008 to stimulate local investment, and we are continuing to promulgate the benefits as widely as possible through initiatives such as the whole system demonstrator sites.

FACTBOX

The whole system demonstrators

In 2008, the Secretary of State for Health launched a programme of whole system demonstrators to look at the benefits of integrated health and social care supported by advanced assistive technologies such as telehealth and telecare.

The evaluation of the demonstrators is the largest of its kind in the world and will assess the impact of the technologies on:

- user-reported quality of life, independence and psychological well-being;
- carers' quality of life;
- patterns of health and social care use;
- practitioners' working lives and relationships with patients/service users;
- clinical effectiveness;
- cost-effectiveness of care.

Three sites have been established – in Cornwall, Kent and Newham – and will introduce over 6,000 people to telecare and telehealth over a two-year period. As part of the evaluation, 660 carers will be questioned.

The demonstrators will lead to a better understanding of the level of benefit associated with such developments. They will also help to fast-track future change by addressing the key implementation barriers and providing solutions for the wider NHS and social care sector.

Housing, leisure and transport

3.25 As outlined by *Lifetime Homes*, *Lifetime Neighbourhoods*, good housing makes a critical contribution to the value and effectiveness of the health and care systems. That strategy will play a key role in helping services to be better joined up. It will relieve a significant part of the stress on carers and those being supported by encouraging housing providers to work

with other agencies to identify new ways of bringing services together around a common agenda of prevention, personalisation, co-ordination and integration. Specifically we will be working to:

- test a preventative predictive risk approach (which will identify older people at risk of needing high levels of care and support, thus allowing for earlier interventions) in suitable locations from 2008;
- develop national information and advice on housing and related areas such as care and finance, ensuring that this is developed with consideration of appropriate links to the carers' helpline;
- integrate housing support into the Common Assessment Framework for adults (see Chapter 2);
- develop the single assessment process to promote joined-up health, housing care and benefits assessment;
- support local authorities and PCTs with their new statutory status as named partners in their duty to agree and deliver a single set of priorities for their local area (as set out in the Local Area Agreements).

Housing association partnership in North Wiltshire

Carers Support North Wiltshire (CSNW) worked with Westlea Housing Association (WHA) to cross-reference the two organisations' databases. They found that over 45 per cent of carers on the CSNW database lived in a WHA property, and of those over 40 per cent were parent carers. As a result, WHA has provided £16,500 per year for three years to develop a volunteer co-ordinator/activities worker who will help sustain tenancies and support carers.²³

CASE STUDY

3.26 Carers often find it difficult to access services in the community even when they have the time to do so, owing to those services' lack of accessibility. This can contribute to their inability to lead a life outside their caring role.

23 *Putting People First without putting carers second*, PRTC and Crossroads, 2008

- 3.27** There are things that can be done at local level to try to ensure that this is not the case.

Carer's Card

The London Borough of Hackney offers a Carer's Card to people who provide care for Hackney residents. The card, which is free of charge, provides discounts at over 50 local businesses in Hackney, who voluntarily participate in the scheme. In addition, carers can enjoy concessionary rates for use of swimming, gymnasium and a number of other leisure centre facilities. The scheme also allows for referral to other support for carers where appropriate. There are plans to expand the scheme into libraries – for example, by offering extended borrowing times and waiving fees.

CASE STUDY

- 3.28** A number of local authorities run schemes that recognise the contribution carers make to society, and we want to build on these. Some offer discount schemes for transport and leisure facilities for carers, regardless of whether the carer is accompanied by the person they care for; this goes beyond the discounts available to carers when they are accompanying the person they support through schemes such as the disabled person's railcard and concessionary bus fare schemes. These discounts can play a big part in allowing carers to take part in the sort of activities that others take for granted, and can help to address carers' isolation.
- 3.29 New commitment:** In recognition that much good work is already happening, we will be working with local government to make sure that this good practice is spread more widely. There is an extensive range of existing methods for communicating good practice among local authorities, and we will be integrating schemes that benefit carers into these.

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.

Sharing of best practice in supporting carers across local authorities.

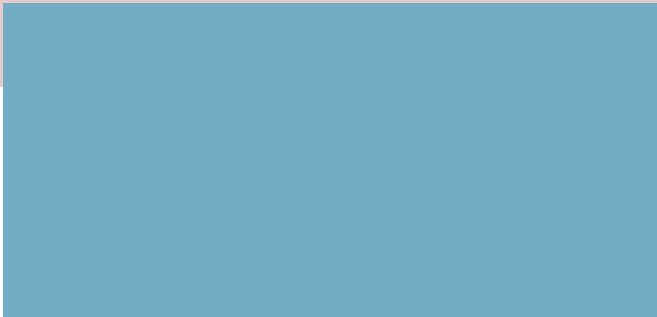
Longer term: Identified priorities

Consideration of further increases in break provision, 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 garnered in the pilots.

In the context of community empowerment and the reform of the care and support system, we will 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.

Chapter 4: Income and employment



Consultation: What carers have told us

Improving the financial position of carers was noted as an important consideration by participants during the consultation. There was broad support for targeting financial benefits to those carers in the greatest need, in particular those who provide the most hours of care and those with the greatest financial hardship.

“Carer’s Allowance does not reflect the work which goes into caring.”

“Carers are too isolated. If carers do not have money then they are unable to make the most of life.”

Carers also want the opportunity to be able to combine paid employment with their caring role, which would both improve the financial position they are in and increase their opportunities to have a life outside caring.

“It is difficult to work. [Carers] do not have the flexibility to work late, etc.”

“Some carers cannot work even when they want to, as this can compromise Carer’s Allowance.”

Our vision is that:

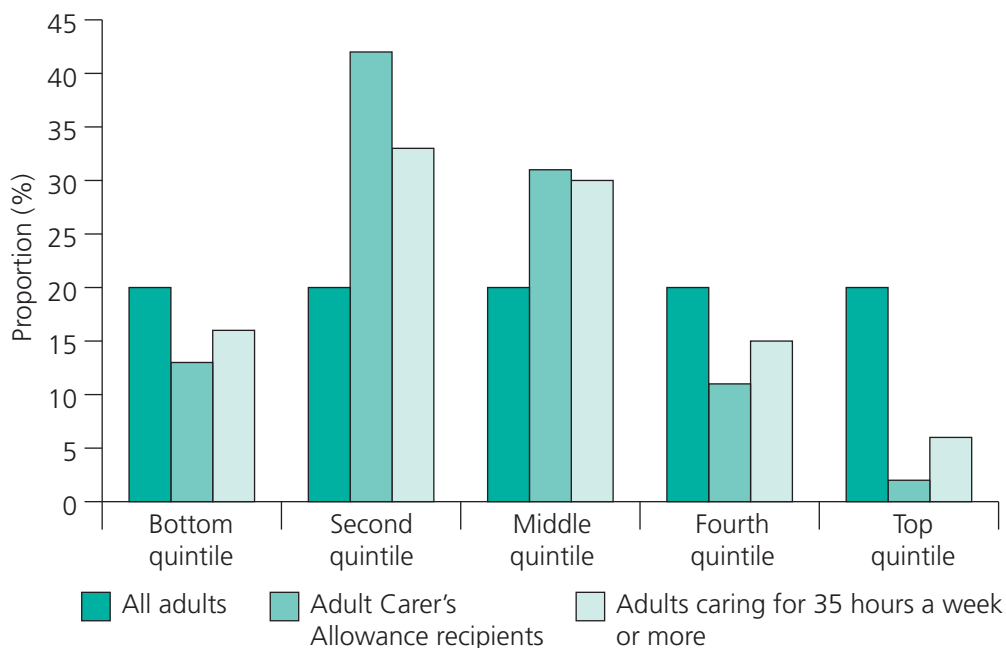
Carers will be supported so that they are not forced into financial hardship by their caring role.

What this means

- 4.1** For many carers, particularly those providing regular and intensive support, the impact of their caring role on financial security can be significant. The current system of financial and employment support for carers could be better focused on minimising hardship. Although carers are no more likely to be in poverty than the general population,²⁴ they do tend to have lower incomes.

24 Households Below Average Income statistical reports 2005/06, Department for Work and Pensions

Figure 5: Distribution of income by hours of care



Source: Family Resources Survey 2005/06, Department for Work and Pensions, 2006, before household costs

4.2 Figure 5 shows that those providing 35 hours or more of care a week and those in receipt of Carer’s Allowance are more likely to be in the second lowest and middle income bands than the general population.

4.3 Society benefits greatly from the care that family and friends provide. It is therefore reasonable for the Government to provide help and support to ensure a minimum level of income for carers who are unable to work. A key goal for this strategy must be to look at the groups most at risk and consider what must be done to protect them.

FACTBOX

Seventy per cent of caring is done by women who are then particularly disadvantaged.²⁵ This can affect their income throughout their lives, both during their caring role and after, if reduced earnings limit what they can contribute to a pension. The National Insurance carer’s credit, due to be introduced in 2010, will help mitigate this to some extent.

25 Yeandle, S. et al., *Carers, Employment and Services Study and Diversity Caring – towards equality for carers*, for Carers UK, Leeds, 2006/07

4.4 While the benefits system can provide a safety net, the most reliable and sustainable means of ensuring that carers can enjoy a reasonable level of income is if they, where possible, combine paid employment with their caring role. Carers providing more hours of care are less likely to be in paid work and so have a higher risk of poverty.²⁶ The large majority of working-age carers are in paid work and over 40 per cent of those who do not work say they would like to do so, either now or in the future.²⁷ Through the provision of better services for the person being supported, increased break provision, easier access to training and skills and encouraging more flexible working opportunities, we want to ensure that carers, where appropriate, are able to combine paid work with caring.

Income

4.5 Since 2001, we have introduced a number of measures to help improve financial support for carers. Depending on their circumstances, carers also have access to the full range of social security benefits, which provide greater support to those households with the lowest incomes. A carer entitled to Carer's Allowance may also qualify for other benefits, such as Income Support or Pension Credit with additions to the standard rate to recognise their caring responsibilities. Parent carers may also be eligible for tax credits.



²⁶ Family Resources Survey 2005/06, Department for Work and Pensions, 2006, before household costs
²⁷ Yeandle, S. et al., *Managing Caring and Employment*, Carers, Employment and Services Report Series, no. 2, for Carers UK, Leeds, 2006/07

Improving the income and health of hidden carers in St Helens

Partnership working between St Helens Council and the local Princess Royal Trust for Carers' Centre to identify and support hidden carers resulted in carers and their families receiving £569,200 of additional income in one year. By making carers aware of the benefits they were entitled to, the average family was better off by £53.60 per week.

Joint benefit take-up campaigns and road shows during 2005 identified the need for specific work to be focused on carers with access to specialist benefit advice. St Helens Council, recognising the importance of supporting carers, included finding hidden carers in its Local Area Agreement in 2006.

This new approach found that some families had lost out on thousands of pounds of unclaimed benefits in the course of their caring lives, and up to 63 per cent of known carers were not claiming all the benefits they were entitled to. In addition, many carers said financial worries were affecting their own health: 57 per cent had one or more health problems.

Carers' support workers ensure that all carers are able to access income and benefits advice and health checks at the Carers' Centre. Health trainers (Lottery funding) from the Healthy Living Team (PCT and local authority funding) are available at the Carers' Centre.

CASE STUDY

- 4.6** For lower income carers, we raised the carer premium in the income-related benefits in 2001 by £10 over and above the normal annual increase in line with prices. Over 223,000 carers in receipt of Income Support now benefit from this change. When Pension Credit was introduced in 2003, we set the corresponding additional amount for carers at this higher rate. Over 234,000 pension age carers now receive this additional amount. The rate of the premium/additional amount was

raised to £27.75 in April 2008. We also removed the 65 age limit for new claims to Carer's Allowance in 2002.²⁸

- 4.7** Carers under State Pension age who are entitled to Carer's Allowance accrue a National Insurance credit for each week that they meet the Carer's Allowance entitlement conditions. From 2010, we are introducing a National Insurance carer's credit for carers under pension age providing at least 20 hours of weekly care, to recognise their need to protect their rights to the State Pension and State Second Pension.
- 4.8** Carers need to be able to access good advice about the range of benefits and help that is available to support both them and the people they care for. The introduction of the carers' helpline will help to make this information more easily accessible.
- 4.9** The key finding of the Income Task Force is that carers are a disparate group, with widely differing caring responsibilities and support needs. The current system of carers' benefits does not reflect this diversity.
- 4.10** We acknowledge that the current structure of benefits for carers needs to be reviewed. Within the context of wider welfare reform and the fundamental review of the care and support system, we must create a system of carers' benefits that is able to provide support where it is most needed and that can adapt to the wide range of needs that carers have.
- 4.11** In doing this, we will adopt the main principles that the Income Task Force recommended should be used to guide reform. These are:
- to recognise the contribution that carers make to society;
 - to make it easier for carers to combine caring with work, or preparing for work;
 - to reflect the diversity of carers' circumstances and caring responsibilities.
- 4.12** We acknowledge that the longer-term reform of support for carers must create a flexible system that reflects these principles, while still ensuring that we achieve our aspiration for simplicity and alignment across the benefits system.

Employment

- 4.13** Enabling carers to combine their caring role with paid employment is a key ambition in trying to mitigate some of the negative financial effects of caring. Currently, carers caring for more than 20 hours a week are much more likely to live in workless households.²⁹ Those in paid work and caring for more than 20 hours a week are more likely to be in low-paid occupations.³⁰ This is likely to affect women more than men with only 32 per cent of female carers working full-time, while 30 per cent are working part-time. Among men, the equivalent figures are 66 per cent in full-time work and 7 per cent working part-time.³¹
- 4.14** To help carers who want to work part-time, we have increased the earnings limit in the Carer's Allowance every year since 2001, and it now stands at £95 a week (following an increase above the normal annual increase in line with prices in October 2007) – almost double its pre-2001 level of £50.
- 4.15** In addition, the Work and Families Act 2006 extended the right to request flexible working to employees who care for an adult. This builds on the introduction of the right to request flexible working for parents of children under the age of 6 (or 18 if the child is disabled).
- 4.16** An awareness-raising campaign will be launched later this year to ensure that carers, the people they support and employers across the country are aware of the rights and the benefits flexible working can bring.
- 4.17** Currently, the right to request flexible working applies only where the person being cared for is a spouse, partner civil partner or specified relative of the carer, or where the person cared for lives at the same address as the carer. The scope of the current legislation means that around 20 per cent of carers, many providing significant levels of care, are denied this right. We will review the definition of a carer in the legislation with a view to extending the right to request flexible working to all carers.

29 *Carers, Employment and Services: time for a new social contract?* Carers, Employment and Services Report Series, no. 6, Leeds, Yeandle, Sue et al., 2007

30 General Household Survey, Office for National Statistics, 2000

31 Yeandle, S. et al., *Carers, Employment and Services: time for a new social contract?* Carers, Employment and Services Report Series, no. 6, Leeds, 2007

Employers for Carers

Employers for Carers, an organisation of small, medium and large employers, is committed to:

- identifying and promoting the business benefits of supporting carers in the workplace;
- influencing employment policy and practice to create a culture which supports carers in and into work.

Employers for Carers is relaunching as a membership forum for employers, offering a range of support from information on good practice to training and consultancy. A core leadership group, including BT, Unum Provident, Listawood and PricewaterhouseCoopers, will work with Carers UK to offer advice for employers seeking to support the one in every seven members of the UK workforce who are also carers.

Critically, the group will also engage in the debate on care and support services, recognising that, even when employers offer support to working carers, what makes the greatest difference to their ability to juggle paid work with caring responsibilities is the services available to the people they care for.

CASE STUDY

4.18 During the consultation, carers were clear that they wished to have the opportunities available to combine paid work and caring.

“Employers need to be made aware that carers are very committed people who take work seriously – otherwise they would not take their responsibilities as carers seriously.” (Carer at a consultation event)

A working carer who is supported in paid employment

Clive is a 46-year-old police sergeant who has cared for his wife Lucy, 52, for the past five years. He showers and dresses her, deals with her arrangements and plans, and organises her activities. Clive works a four-day week and has compressed hours, meaning he works a full working week in those four days. This makes it easier to plan hospital appointments for Lucy and to do other tasks that make up his activities as a carer. He is grateful to his employers for the flexible working package they have offered him, and they benefit from the skills and experience he is still able to bring to the force.

CASE STUDY

4.19 We agree wholeheartedly with the ambition to help carers manage the balance between caring and work and will try to ensure that, over the next 10 years, all the carers who want to work will be able to do so. This fits in with our wider objectives to maximise employment opportunity for all. Enabling carers to work not only helps them as individuals but also improves the efficiency of the labour market and helps to sustain growth in the economy.

FACTBOX

There are over 1.5 million carers in England aged between 25 and 59 years. Half of these are under 45 years of age³² – prime working age. These people will already have acquired a significant level of skills crucial in a competitive global labour market. 2.2 million people start and stop caring each year and may need support to re-enter the job market.³³

32 Census 2001, Office for National Statistics

33 In the Know, Carers UK, 2008

- 4.20** Jobcentre Plus, which provides help and advice on jobs and training, is currently improving the ways that advisers work with carers. They have produced online guidance for advisers to give them the information to provide an effective service to carers – this guidance gives examples of best practice, and makes advisers aware of many carers’ issues.
- 4.21** If caring responsibilities are found to be an insurmountable barrier to work, then Jobcentre Plus can provide support that will facilitate a smooth transition when the carer or former carer is eventually able to return to the labour market. This may include such things as confidence-building or ensuring that skills remain relevant. Jobcentre Plus advisers can develop personalised plans based upon the individual needs of each carer that will maximise their chances of an early return to employment.



FACTBOX

The circumstances surrounding carers and paid work are often complex and rarely are two people's circumstances the same. To enable staff to better assist carers, Jobcentre Plus has a dedicated online carers' portal.

The site covers:

- benefits information for carers;
- how Jobcentre Plus can support carers;
- information for advisers on carers' issues;
- detail of some of the national and local support available to carers.

The site also provides information on a wide number of topics including:

- advice on attending interviews;
- helping carers assess their assets and appropriate job goals;
- devising work solutions, including crisis solutions;
- advice on how to disclose caring responsibilities to an employer;
- return to work issues including in-work support;
- contacts with other carer support organisations

4.22 Childcare partnership managers have been in place since April 2003, with one in each Jobcentre Plus district. These partnership managers have good local awareness and are able to advise and work with care providers in the public, private and voluntary sectors. They co-ordinate Jobcentre Plus programmes and strategies with other agencies and bodies in order to help parents into work. Research evidence shows that many childcare partnership managers have built successful working arrangements with a wide number of organisations.³⁴

34 Dench, S. et al., *Jobcentre Plus and Children's Centres*, Department for Work and Pensions Research Report, no. 485, 2008

4.23 New commitment: A similar approach will be used in the context of carers. Managers will be able to advise on initiatives that are taking place in the local area, and will be fully aware of care services that can be offered. Furthermore, they can ensure that advisers are kept aware of such things as training opportunities that suit their clients' needs and the care facilities available in the area.

4.24 Such management, coupled with effective training material, should ensure that a better service to carers is offered by Jobcentre Plus staff. The framework for this model already exists in Jobcentre Plus offices as it can build on the success of the Childcare partnership managers. Although carers' and lone parents' requirements are not identical, they do have some parallels.

4.25 New commitment: It can often be difficult for carers and advisers to assess whether a vacancy would meet their needs. Vacancies need to be effectively marked as being suitable for a carer, especially in terms of the flexibilities the employer can offer. We will enable Jobcentre Plus to promote in a more proactive way the advantages of greater flexibility to employers in terms of increasing the potential pool of applicants for their vacancies. This would facilitate more effective job matching and easier job searches for those for whom flexible working is an important factor.

4.26 New commitments: There is no carer-specific programme within the current system and few carer 'experts' within Jobcentre Plus to deal with the special needs of carers. We will therefore improve the help and advice available to carers wishing to re-enter the labour market by:

- improving information about flexible job vacancies in Jobcentre Plus job banks;
- introducing care partnership managers in every Jobcentre Plus district;
- introducing specialist training for Jobcentre Plus advisers who work with carers;
- funding replacement care for those who are participating in approved training;
- ensuring carers have access to appropriate employment programmes;
- the Department for Work and Pensions (DWP) and Jobcentre Plus investigating the feasibility of providing return to work support through third sector organisations.

Partnership working: Jobcentre Plus and the Carers Centres, Oxfordshire

The three Carers Centres in Oxfordshire and Oxfordshire County Council are developing strategic links with Jobcentre Plus in order to help them raise awareness of carers and key issues: how to identify carers and how to support and signpost them to the local Carers Centres. A pilot awareness-raising programme for front-line Jobcentre Plus staff was delivered by the Oxford Carers Centre, backed up by information packs for each member of staff.

CASE STUDY

Employers

- 4.27** The role of the employer, small, medium and large, is crucial in enabling a carer to combine paid work and caring. It is not just the offer of flexible working but a recognition of the specific needs of carers, at work, such as access to a telephone if the person they support needs to call them or an understanding that at certain times the carer may have to leave suddenly.
- 4.28** Currently, more than 3 million people – one in seven of the workforce in the UK – juggle the responsibilities of caring and paid employment and this is in part due to the flexibility that not just large but also small and medium employers provide for their employees.

A small employer who supports carers

A solicitors' firm in Sunderland and Newcastle employs 70 people, and ensures support for carer employees. In recognising the importance of a work–life balance, it works closely with Sunderland Carers Centre to understand what matters to carers, and what would help them in their caring roles. Staff receive a yearly appraisal that includes a discussion of their role as carers. Senior staff also ensure that issues surrounding caring are discussed, and devise solutions to enable staff to balance working and caring.

Policies and procedures exist to support flexible working, including home-based working. Feedback from staff shows the importance they place on this flexibility.

CASE STUDY

4.29 It is not just a one-sided relationship – employers can see substantial gains in employing or retaining carers as employees.

4.30 New commitment: Although many employers already enjoy the advantages that employing carers can bring, others remain to be convinced of the benefits. We will therefore work with business to produce a good practice guide for all employers on the benefits of employing carers. The guide will include case studies and focus on the business case for employing carers. It will be disseminated throughout the business community.

Flexible working at BT

Three-quarters of BT's 100,000-strong workforce work flexibly. The company has identified the following benefits:

- productivity gains averaging 21 per cent for employees working flexibly;
- cost savings, including £1 billion in office costs and equipment for home workers;
- greater customer satisfaction – BT's customers report that the quality of service has risen by 5 per cent since flexible working was introduced;
- more creativity and energy because flexible working produces twice as many new ideas;
- reduced sick leave – less than three days a year for home workers;
- staff turnover is less than 4 per cent;
- a trust-based relationship with employees that is "worth its weight in gold";
- reduced CO₂ emissions and traffic nuisance – flexible working saves 12 million litres of fuel a year.

Lisa Crowley, personal assistant to a BT senior director, lives with and cares for her elderly mother who has severe arthritis. She juggles successfully the demands of work and caring thanks to an understanding line manager and the chance to work occasionally from home. *"It's sometimes a struggle but the rewards are worth it," says Lisa. "What is reassuring is that I don't feel I have to justify any absence. My manager and colleagues are aware of my situation, and they don't mind if I have to use the phone in office time for personal calls. This makes such a difference to me and my mum."*

Training and skills

- 4.31** We are committed to ensuring that training is provided in a flexible manner so that it can be fitted around caring responsibilities. Many carers are unable to access training and education opportunities because they conflict with their caring responsibilities.
- 4.32** Working carers are more likely to be unqualified and less likely to hold university degrees than other people in employment. Extended periods out of work mean that skills will atrophy and the new skills demanded in a dynamic labour market will not be learnt.
- 4.33 New commitment:** To allow carers to have every opportunity to ensure that their skills are such that they can combine work and caring, we will encourage more flexible opportunities for life-long learning to be made available to carers (for example, through more flexible hours and modular courses), in particular for those who have been out of the workplace. These provisions are often already available for parents who wish to learn flexibly.
- 4.34** This reflects our move towards more demand-led funding systems for colleges which should be more responsive to the needs of the individual learner. From 2010, we will introduce national skills accounts to motivate individuals into learning by giving them greater purchasing power over their training. A key principle of skills accounts is that the flow of public funding to providers will follow learner choice, giving individuals maximum incentive to learn and providers maximum incentive to offer what learners need. Skills accounts will enable carers to update their skills, increasing their opportunity to return to work if they would like to do so. They will also help break the isolation some carers face by offering a life outside caring.

Changing Lives project

The Carers' Resource at Harrogate, Craven and Airedale runs the Changing Lives project which supports carers at their own pace to build confidence and find new training and employment opportunities. Fun and motivating courses are run at times and places that suit carers, covering areas that range from computer skills and interview techniques to confidence-building and individual interests.³⁵

CASE STUDY

- 4.35** We are working to create a more effective and integrated employment and skills system which gives adults the support they need to find sustained employment and to progress in work.
- 4.36** Alongside this we are also developing an adult advancement and careers service which will offer a universal service to adults and provide advice and guidance and other support services. Work will be undertaken to ensure that the adult advancement and careers service has close ties to the new information helpline and website for carers.
- 4.37** The new service will work in close partnership with Jobcentre Plus to deliver a better integrated system. Included in this will be a Skills Health Check which will be personalised; an initial assessment of skills and abilities; identification of career, learning and work objectives; and the skills development needed to meet the individual's goals. The assessment will serve as the starting point for the development of the individual's action plan to progress in learning and work. There will also be access to financial support. The service will reach out to disadvantaged clients, such as carers, making itself accessible through an effective integration of face-to-face, online and telephone-based services.
- 4.38** We recognise that people often have to overcome wider barriers before they are able to progress in learning and work. The adult advancement and careers service will be looking to join up advice services across a range of issues, such as those offered by the new carers' helpline and

website, and including others on housing, employment rights, finance and childcare as well as skills and jobs.

Short term: Commitments

Review the flexible working definition of a carer.

An awareness-raising campaign for employers around the right to request flexible working.

Produce a good practice guide for employers around supporting carers and integrating them into the workforce.

Improve the support offered to carers by Jobcentre Plus by:

- improving information about flexible job vacancies in Jobcentre Plus job banks;
- introducing care partnership managers in every Jobcentre Plus district;
- introducing specialist training for Jobcentre Plus advisers who work with carers;
- funding replacement care for those who are participating in approved training;
- ensuring carers have access to appropriate employment programmes;
- the DWP and Jobcentre Plus investigating the feasibility of providing return to work support through third sector organisations.

Ensure that skills training is provided in a flexible manner so it is accessible for carers.

Longer term: Identified priorities

Reviewing the structure of the benefits available to carers in the context of wider benefit reform and the fundamental review of the care and support system.

Chapter 5: Health and well-being



Consultation: What carers have told us

"Your health is 'postponed' if you are a carer."

"All carers need a carer to cope with the emotional strain you're put under."

"Whenever I contact my doctor for a home visit he knows there is a problem. It is important for GPs to know how to react to carers' problems with health and their issues."

Our vision is that:

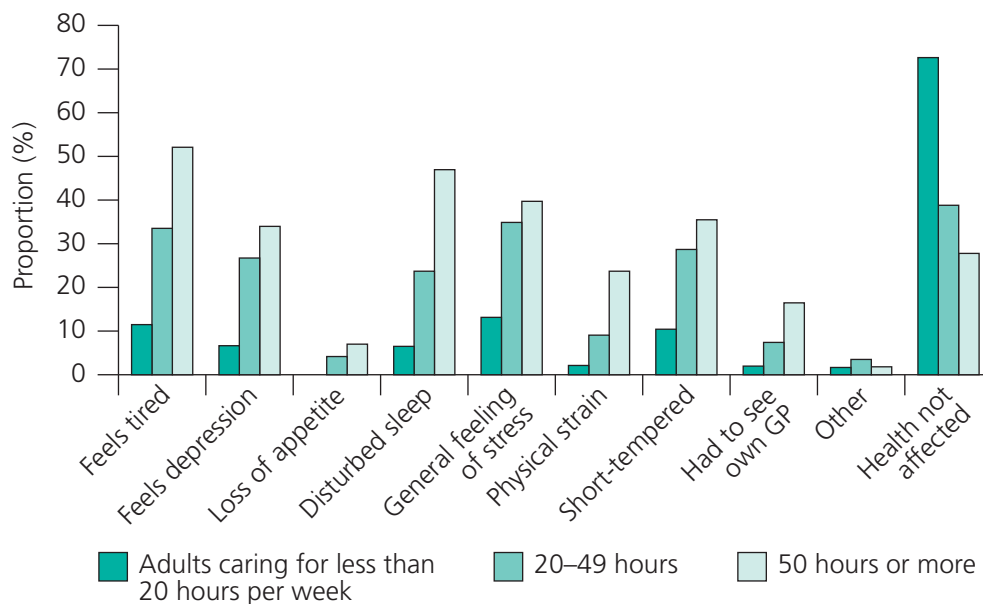
Carers will be supported to stay mentally and physically well and be treated with dignity.

What this means

- 5.1** In the White Paper *Our health, our care, our say* we acknowledged that: "6 million people in this country care for family or friends. About 1.25 million of them provide care for over 50 hours each week. People who provide these long hours of care are twice as likely to be in poor health themselves, and need to be supported both in their own right and in their role as carers."

FACTBOX

Nearly 21 per cent of carers providing more than 50 hours of care report that they are not in good health, compared with only 11 per cent of the non-carer population.³⁶

Figure 6: How caring affects carers' health

Source: *Carers 2000 National Statistics*, HMSO, 2002, using the General Household Survey

- 5.2** This is unacceptable. Every carer should be supported so that caring does not adversely affect their health. Professionals, in both health and social care, should recognise that caring can place physical and mental stress on the carer who may need services and support specifically directed at their health needs.
- 5.3** Carers should not have to ignore personal health concerns and needs because their caring role does not allow the time to address them. The services and support available to carers must be such that they are able to stay mentally and physically well throughout their caring role.
- 5.4** Furthermore, carers should be treated with dignity and respect both as carers and as individuals in their own right. A major step towards achieving this is recognising that carers must be treated by professionals as partners in care, as set out in *Putting People First*.

FACTBOX

Health inequalities

Our document on health inequalities (*Health Inequalities: Progress and next steps*, Department of Health, 2008) reinforces our commitment to achieve the current target on health inequalities (which ends in 2010). It will also look beyond this target to examine how we can prevent health inequalities for disadvantaged groups in the future. The strategy itself recognises that carers are a group at disproportionate risk of experiencing health inequalities and they will form part of the considerations for action beyond 2010.

Emergency break provision

- 5.5** As part of the New Deal for Carers, in *Our health, our care, our say*, we made a commitment to ensure that in each council area, “short-term, home-based respite support is established for carers in crisis or emergency situations”.
- 5.6** In October 2007, every local authority with social service responsibilities was provided with funding (a total of £25 million per annum) for emergency care provision. This funding has been provided in recognition of local authorities’ responsibilities for setting up systems so that carers and the people they support can have immediate access to alternative support in emergency or crisis situations. The funding helps to provide capacity for the local authority to work with carers to ensure that plans are put in place should a crisis cause them to be unable to continue their caring role. This funding assists in ensuring that there is no break in care provision for the person being supported and in so doing gives the carer peace of mind.

Hertfordshire contingency plans for carers

Hertfordshire County Council has developed a process that allows carers and the people they care for to indicate how they would like to be supported in an emergency.

The Hertfordshire contingency plan process allows carers to identify someone who would be willing to be contacted until they are able to return. Planning in advance ensures that individuals will receive the type of support that they need. One way of doing this is through a 'suspended direct payment'. The carer supplies details of an individual who is willing to be contacted in an emergency and the payment is made only if an emergency occurs.

Emergency care could be supplied by a family member, friend or neighbour. Adult Care Services add them to the computer and issue a card bearing the service user's unique number and a telephone number accessible 24/7. Anyone telephoning and quoting the unique number will allow social care staff to access the contingency plan and put it into action.

CASE STUDY

Prevention

- 5.7** We also know that prevention and early intervention measures can make a significant contribution to supporting individuals to manage their own health.

FACTBOX

NHS Choices

The Department of Health has developed a website – NHS Choices – which is a source of information on hospitals, treatment and lifestyles. Over the next months and years, people will be able to use NHS Choices to obtain much more information to help them make decisions about their care. NHS Choices will also provide the website services linked to the carers' helpline. This can be accessed via www.nhs.uk

- 5.8** NHS Mid-life LifeCheck will offer people aged between 45 and 60 the opportunity to assess their health and lifestyle by carrying out an online risk assessment questionnaire. The behaviour change section gives people the chance to design a personalised plan to improve their health and well-being. Mid-life LifeCheck will assist carers by providing practical advice on where to seek help and the opportunity to improve their lives.
- 5.9** On 1 April 2008, the Department of Health announced that everyone between 40 and 74 years old will be invited for a vascular check to assess their risk of vascular disease – that is, coronary heart disease, stroke, diabetes and kidney disease. Each check will be followed up with an individually tailored assessment setting out the person's level of vascular risk and what steps they could take to reduce it. This will provide huge benefits for some carers, not just in terms of dealing with any problems that the vascular check will pick up but also through bringing them into contact with health professionals.
- 5.10 New commitment:** Building on these initiatives, and in response to demand during the consultation, we are piloting annual health checks for carers in a number of primary care trust (PCT) areas. It is envisaged that these health checks will focus on carers in the highest intensity roles.

*“An annual health check for carers is an initiative which could help pinpoint early signs of deterioration in carers' health and well-being.”
(Idea from the consultation)*

- 5.11** It is our belief that annual health checks will give both carers and health professionals an opportunity to detect and deal with, at an early stage, any emerging health problems the carer may have. This will enable them to care for longer periods while remaining in good health.
- 5.12** The health check pilots will collect evidence as to the cost-effectiveness of this particular initiative and the benefits that both the health service and carers feel they derive from them. Subject to a positive evaluation, we will explore the possibility of extending these health checks more widely.
- 5.13** We will also explore the possibility in the longer term of providing replacement care to allow carers to attend hospital appointments and screenings (cancer, vascular disease, etc.). This will seek to ensure that carers' vital health issues are not compromised by their caring role.

NHS Choice

- 5.14** Carers often find that their caring responsibilities prevent them from accessing health services both for their own needs and on behalf of the person they support. It is important, therefore, that both carers and the people they care for are given as much choice and control as possible when accessing NHS services. We are introducing a number of measures that seek to improve the choice and control offered by the NHS for service users.
- 5.15** From 1 April 2008, PCTs are expected to provide more choice for people with long-term health conditions. For these people and their carers, choice means working more closely with their health professional and being given options over how to manage their condition as part of agreeing a personalised package of treatment and care. As part of this process, carers should be supported to make decisions about their own lifestyle, culture, preferences, circumstances and priorities.
- 5.16** Choice will be further promoted through personalised and integrated care planning. By 2010, we are committed to ensuring that everyone with a long-term condition will be offered a care plan. Guidance for commissioners is planned for publication in summer 2008. It describes care planning as a process, centred on the person, which discusses their social, psychological and physiological needs. The process sees the person "in the round", recognising that many factors have an impact on health and well-being. Co-ordination of care is another key element of

the care planning process which relieves carers of some of the difficult care co-ordination role. Guidance emphasises that the needs of carers should be built into the care planning process.

Wirral GPs supporting carers

Wirral PCT has developed a computer template that records health and social care data on patients who are carers and registered with a GP. Local GP practices are now able to offer carers appointments that can be tailored around their caring responsibilities. Carers are also offered access to other health and social care information and services once they have been identified as carers within their GP practice.

CASE STUDY

- 5.17** From 1 April 2008, the full roll-out of patient choice means that the majority of patients being referred to secondary care will be able to choose where they wish to be treated. When combined with the Choose and Book system, which gives patients a choice of place, date and time for their first outpatient appointment in a hospital or clinic, carers will see significant improvements in the flexibility of provision of NHS services. This should provide benefits for carers in terms of enabling them to arrange convenient appointments for themselves and the people they support.

Emotional support

- 5.18** A representative study, based on analysis of the British Household Panel Survey, found that carers were more likely to report high levels of psychological distress, including anxiety, depression, loss of confidence and self-esteem, than non-carers.

“Health professionals don’t recognise depression in carers. We get pigeon-holed and marginalised rather than helped to cope.”
(Carer at a consultation event)

- 5.19** This stress can be the result of being on call for long periods of the day and may lead to the deterioration of relationships. Stress may mean that carers neglect their own health, for example by not eating properly, or they may neglect, or even mistreat the person they are caring for. It is very important that this kind of stress is recognised – both by carers themselves and by professionals in contact with them – at an early stage and potentially abusive situations are tackled.
- 5.20** The National Institute for Health and Clinical Excellence (NICE) guidelines say that people with depression and anxiety disorders, unless these are very recent or very mild, should be offered an evidence-based psychological therapy, such as cognitive behavioural therapy, as an alternative to anti-depressants.
- 5.21** We have committed additional investment rising to £173 million per year by 2010/11 to developing psychological therapy services across England. The basic service model envisages a team of therapists within a PCT taking referrals from GPs, as well as self-referrals, and delivering NICE-compliant therapies at the level required in convenient settings in primary care or elsewhere in the community.
- 5.22 New commitment:** In addition, we recognise the important role that the third sector plays in providing emotional support to carers. As part of the Department of Health review of grants to third sector organisations, we are considering identifying projects offering emotional support to carers as a priority category.



FACTBOX

End of Life Care Strategy

Assessing carers' emotional, practical and physical needs, identifying any potential risk factors and agreeing a care plan with carers should be an important prelude to bereavement care. The specific needs of bereaved children and adolescents should also be recognised and information and support given in a way that is sensitive to their maturity and level of understanding.

It is important that information on how to access comprehensive and culturally appropriate bereavement and support services is available from all health, social care and other emergency organisations providing care at the end of life and into bereavement.

The importance of carers throughout the caring process, including into bereavement, will be highlighted in the forthcoming End of Life Care Strategy.

Commissioning

5.23 The important part that primary care plays in providing help and support to carers was a consistent theme under discussion in the consultation events. Primary care is very often the first point of contact with services. However, it became clear in discussions with carers that such support is variable.

The Carers' Resource in Harrogate

The Carers' Resource provides details to individual GP practices about which carers it is supporting and which it is not. This enables more successful and targeted outreach and early intervention.

"During the period of my mum's illness, the Carers' Resource staff were the only people to pick up the phone and ask how I was. It was so lovely to hear their cheerful voices when I was trying to deal with all the problems. The information they gave me was invaluable." (Carer)

"It's great having someone available to refer my patients (who are carers) to; knowing they will definitely get the help and support they need. Before Anne [the Care Support Officer] started I listened to distressed carers but really couldn't offer definite advice and didn't know where to get them appropriate support. It was very frustrating." (GP)

CASE STUDY

5.24 Significantly, the Operating Framework for the NHS, which sets out the specific business and financial arrangement for the NHS in any given year, in 2008/09 makes, for the first time, specific references to supporting carers. It sets out an expectation that:

"PCTs should aim to create a more personalised service that provides support for carers [...] by recognising their need for breaks from caring."

5.25 This will make clear to health professionals that providing breaks when they feel these are necessary for the health and well-being of the carer is part of the work of the NHS. This is a major step forward in term of support for carers and has the potential to ensure much greater joint working between agencies, particularly regarding the provision of breaks.

- 5.26** In December 2007, the Department of Health launched its vision for the World Class Commissioning programme which is seeking to transform the way health and care services are commissioned in order to deliver improved health outcomes.
- 5.27** One of the 11 competencies of the World Class Commissioning programme concerns engagement with the public and patients to shape services. Carers should be encouraged to become involved, not just through mechanisms like Local Involvement Networks (LINks) but every time they encounter health professionals, to make their voices heard and influence the commissioning of services so they are tailored around their needs.
- 5.28** To complement the reference in the Operating Framework, the new guidance on Practice Based Commissioning³⁷ also makes specific reference to the ability of GPs to commission breaks:
- “PCTs should consider a menu of interventions including the purchase of respite care to allow carers to take a break.”



37 Practice Based Commissioning – budget setting refinement and clarification of health funding flexibilities, incentive schemes and governance, Department of Health, 2007

FACTBOX

Practice Based Commissioning

Practice Based Commissioning (PBC) is a scheme through which GP practices voluntarily take on the management of the health and care budget for people registered at their practice and work closely with the PCT to design and commission a range of services that best meet the needs of their local practice population. PBC is our most powerful way of reaching into local communities and provides clinical leadership of World Class Commissioning to improve health outcomes and reduce inequalities.

The *NHS Next Stage Review: Interim report*³⁸ encouraged practice-based commissioners and PCTs to be more flexible in using NHS funds to secure alternatives to traditional NHS provision where there is clear benefit to the NHS and individual patients. This could be to allow carers to take a break, for example in families of children with a disability, or when patients with a terminal illness need more intensive nursing for a fixed period of time.

For further details about this and other examples of how funds can be used more flexibly see PBC guidance published on 17 December 2007: www.dh.gov.uk/psc.

- 5.29** With the advent of initiatives such as LINKs, World Class Commissioning and PBC, the NHS has now sent an unambiguous signal that it should take greater responsibility for supporting carers. Whether it be through third sector organisations or individual involvement there is a real opportunity here, one which cannot be overstated.
- 5.30** Absolutely key to ensuring that the right commissioning decisions are made to achieve the outcomes of the service user is user involvement in the decision-making process.

- 5.31** There is a move in both health and social care services to ensure that those who use these services are able to directly influence commissioning decisions. From 1 April 2008, local authorities with social service responsibilities have been provided with funding to establish and support LINks activities (£84 million between 2008 and 2011). They give carers the opportunity to engage directly with health and social care commissioners and service providers and make recommendations on how services can be improved.
- 5.32** As part of *Aiming high for disabled children* we are investing £5 million to provide support for local areas so that they can successfully increase the participation of parents as well as provide direct support to assist parents themselves to become more actively engaged. Support will be targeted to those areas with the greatest need. This will help ensure that the voice of the parent is heard by those who commission services and is part of the wider user involvement agenda across government.

Partners in Policymaking

Partners in Policymaking (PIP) is a national network of disabled people, family members and friends. PIP runs leadership development courses for disabled adults and parents or relatives of disabled children who think that life for disabled children and adults could be better and want to improve the way things are now – but don't know where to start.

After completing the courses people use what they have learned in lots of different ways. Les Scaife set up the West Lancashire Peer Support Group, an organisation that offers support and advice to families and individuals. Les recently visited Australia to share what he has done here, and is working with people in Cornwall to set up a similar support organisation.

CASE STUDY

GPs

5.33 GPs are often the first point of contact for carers and will normally continue to be the professional in closest contact with them. There is, however, a large variation in service provision.

“My GP is fantastic. He involves me and seeks my views in the appointment for the person I support and then takes time to deal with any health concerns I may have.” (Carer at a consultation event)

5.34 The Quality and Outcomes Framework (QOF)³⁹ was first introduced as part of the GP contract in 2004. It provides pay incentives to GPs when they meet certain criteria. Three QOF points relate to carers:

“The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment.”

5.35 These QOF points provide an incentive for GPs to provide support for carers in their practices, although more needs to be done to ensure this is an outcome rather than a process-driven measure.

5.36 In the longer term, we have identified that we need to discuss with GPs and other health professionals the measures that can be taken to give a sharper focus to the distinct needs of carers.



Joint work with Manchester Primary Care Trust

In recent months, Manchester's Carers Strategy Team has been working closely with the local PCT to improve services to carers within primary care.

Manchester PCT has a carers' lead and is looking at ways to create a "gold standard", that if met will be published on the carers' website and encourage further identification and referral of carers.

Work is also under way on the current QOF indicator that requires GP practices to establish a mechanism for referring carers to their local authority for a carer's assessment. The newly developed standard would only be awarded to practices who record an expected number of referrals per year. Adding this "gold standard" will ensure that practices have targets and therefore will increase the number of carers referred to social services for an assessment.

An online toolkit to raise awareness of carers' issues and make recommendations on how to improve practice-based services to carers will be launched to accompany the "gold standard" as part of Carers' Week in June 2008.

CASE STUDY

- 5.37** In September 2006, the Princess Royal Trust for Carers and the Royal College of General Practitioners (RCGP) launched a two-year partnership designed to improve knowledge and understanding of carers and carers' issues among primary care professionals.
- 5.38** This led to a good practice guide, highlighting the needs of carers and carers' health, launched in October 2007, and a further action guide for GPs and their teams, due to be promulgated in summer 2008.
- 5.39** The benefits to carers of such a partnership are self-evident in terms of better support being offered by GPs to carers in their caring role and for

their own health needs. In addition, a partnership such as this signals the direction of travel which will ensure closer working between the third sector and health and social care organisations to achieve the best possible outcomes for the carer.

5.40 New commitment: Building on this initiative, the Department of Health in partnership with the RCGP will work to develop, pilot and evaluate a training programme for GPs to help them better to understand carers' needs. This will help ensure that they are able to provide more personal support in recognition of the contribution that carers make to the care of the person being supported.

5.41 The modules on the training programme will be tailored to the needs of specific groups of carers (for example, young carers or particular groups of black and minority ethnic carers) and the content will be developed in conjunction with carers themselves. Furthermore, we hope that carers will be actively involved in providing the training to the GPs.

5.42 Subject to a positive evaluation, this training programme may be rolled out nationally, training thousands of GPs to understand and support carers. The lessons learned from the pilots might also, in the longer term, influence the initial training that doctors receive before they qualify as GPs.

Carers' Recognition project, Guildford and Waverley

A Carers' Recognition project has been developed in the Guildford and Waverley areas, working in partnership with Surrey PCT and carers' support groups. A Carers' Recognition support worker for GP surgeries has been appointed to explain to GPs the benefits of identifying carers and referring them to sources of advice and support. This project will now be extended across Surrey.

CASE STUDY

Partners in care

5.43 One of the core components of a transformed adult social care system, set out in *Putting People First*, is:

“Family members and carers to be treated as experts and care partners other than in circumstances where their views and aspirations are at odds with the person using the service or they are seeking to deny a family member the chance to experience maximum choice and control over their own life.”

5.44 For the first time in a government document, this enshrines the concept of carers as partners and experts in care. This represents a considerable step towards achieving the ambition of treating all carers with dignity and respect. Central to this will be the involvement of carers in all care planning from diagnosis to discharge and beyond. The workforce proposals (set out in Chapter 2) will be instrumental in ensuring that this happens.

5.45 Treating carers as partners in care will also ensure that the health or social care professional takes into account the health of the carer to ensure that there is continuity of care for the person being supported.

FACTBOX

National Dementia Strategy

The draft national dementia strategy is due to be published in summer 2008 with the final strategy and implementation plan published later in the year following a full consultation. The strategy recognises the importance of supporting the carers of people with dementia to ensure improved outcomes for both carers and the people they are supporting.

5.46 Key to treating carers as partners in care is providing them with information relevant to the care and needs of the people they support. *Our health, our care, our say* made a commitment to improve the access to information for everyone with a long-term condition, and their carers, through the introduction of information prescriptions.

Hospital based resources for carers in East Sussex

Care for the Carers and East Sussex hospitals NHS Trust have produced a range of resources for supporting carers. These include a good practice guide for hospital staff covering topics such as information sharing, a carers' information leaflet and a Care Passport, which allows carers to record the special needs, preferences and ways of communicating with the person they care for.⁴⁰

CASE STUDY

- 5.47** Information prescriptions will be issued by health or social care professionals and will guide carers to relevant and reliable sources of information, specific to their needs and locality, to allow them to feel more in control, enable them to provide better-informed assistance for the people they care for, thus helping them to maintain their independence.
- 5.48** Information prescriptions are part of the person-centred care approach which is a consistent theme running through the Department of Health's vision for everyone who uses health services and social care. They should enable people with long-term conditions and their carers, from the point of diagnosis, to make better informed choices when planning care and getting on with their lives. Information prescriptions will also support professionals in sharing information with those who use services and assist them in their role of navigating people around the system.
- 5.49** Furthermore, Lord Darzi's *Next Stage Review of the NHS*, which will publish its final report in summer 2008, will appropriately reflect the importance of carers being treated as expert partners in the NHS.
- 5.50** Building on the move towards treating carers as expert care partners, we will work to establish the legislative or other requirements needed to enable carers to receive appropriate information, especially in cases where mental capacity is an issue.

Caring for a person with mental health problems

Over the 10 years since Mabel's son Mike was given a diagnosis of schizophrenia, the family has experienced a series of peaks and troughs which frequently related to the professionals' attitudes to Mabel, especially their interpretation of confidentiality issues.

In 2007 Mike was relapsing in a serious way, so, having been dismissed by all the professionals, Mabel made a formal complaint.

The first response Mabel received said that Mike had a good care package but because of patient confidentiality she wasn't allowed to know what it was. This was despite Mabel providing over 120 hours of care per month against Mike's care co-ordinator's half hour.

The Healthcare Commission upheld Mabel's complaint, commenting: "the attitudes described led to plans being made without the valuable information of a carer who had first-hand knowledge of the situation."

As a consequence, an information-sharing policy is now in place and Mabel works closely with Mike's team.

CASE STUDY

Short term: Commitments

Piloting health checks for carers.

GP training pilots.

Improving the emotional support offered by third sector organisations to carers.

Longer term: Identified priorities

Develop a full training package for all GPs, dependent on the result of the pilots.

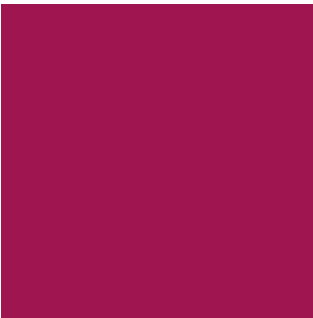
Consider providing carers across the country with annual health checks.

Consider providing replacement care for carers to attend hospital appointments and screenings.

Discuss with GPs and other health professionals the measures which can be taken that will give a sharper focus to the distinct needs of carers.

Work to establish the legislative or other requirements needed to enable carers to receive appropriate information especially in cases where mental capacity is an issue.

Chapter 6: Young carers



Consultation: What young carers have told us

- Young carers were particularly concerned about gaps in support for the person they care for. They also highlighted their own difficulties – the worry they experience and the lack of time to learn, socialise and to access the opportunities other young people have. They believe more needs to be done to address these issues.
- Many feel GPs, hospitals and schools do not always recognise or take account of their needs as children and as young carers, adding to the pressures and challenges they face. Many value the more specialised help which young carer projects and other targeted services provide.
- Young carers' main concerns were: lack of reliable support for the person cared for and the wider family; gaps in emergency support; not enough short breaks and project-based support for the young carers themselves; and lack of understanding and support from GPs, schools and other front-line settings.
- The importance of closer joint working across adults' and children's services was highlighted during the consultation. In particular, the need for support and care for parents who are ill or disabled that takes proper account of the needs of dependent children and so protect them from taking on inappropriate levels of caring.

"My dream is to go to university and it has always been in my head that I wouldn't go to university too close [to home] because it was my way of gaining independence. However, I am not sure I can go because it means leaving home and there isn't the support there for everyone else if I go."

"If we miss out on opportunities, we feel we miss out on some childhood".

"I shouldn't have to choose between my family and my future."

FACTBOX

Young carers

The 2001 Census indicated there are 139,000 children and young people under 18 in England and 175,000 in the UK providing some care to family, friends or neighbours. The majority care for up to 19 hours per week. Across England, 16 per cent (22,000 children and young people) are reported to be caring for between 20 and 50 or more hours per week.⁴¹

Our vision is that:

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.

What this means

- 6.1 Many young carers value the contribution they are able to make within their families. Caring can be a positive experience, helping to foster maturity and independence and strengthen family ties.⁴²
- 6.2 However, extensive or inappropriate caring can be damaging, constraining young people's time and contributing to poor outcomes. Research indicates that school attendance, educational achievement, and emotional and physical well-being can all be affected.⁴³ Young carers can be at greater risk of social isolation and bullying. The transition to adulthood and independence can bring particular difficulties.⁴⁴
- 6.3 We cannot quantify precisely the number of young carers who are adversely affected in these ways nor how sustained the effects are. However, the consultation and broader evidence indicate that too many young carers continue to experience difficulties and are not accessing the support they and their families need.

41 Census 2001, Office for National Statistics

42 Aldridge and Becker, *Children who care: inside the world of young carers*, 1993

43 Dearden and Becker, *Young carers in the UK: The 2004 Report*, 2004

44 Becker and Becker, *Young adult carers in the UK: interim briefing paper*, 2008

Caring for a sibling

Tim is 16 and has Asperger's Syndrome. His behaviour is often aggressive, unpredictable and destructive. Gemma, his sister, who is 12, plays an important part in helping her mother manage his behaviour. She helps to "keep an eye on" Tim and occupies him when he comes home from the day centre. She helps when Tim has a dentist's or doctor's appointment by going with him and their mother and "doing it first", which makes it easier for Tim to carry out tasks or activities that are unfamiliar to him. Gemma gives up a lot of her free time to help with tasks such as cooking, shopping and cleaning, as her mother is often occupied with supporting Tim. However, Gemma is bullied at school. Gemma loves her brother but does not want to be involved in supporting him quite so much as she wants the bullying to stop and to "have a life".

CASE STUDY

6.4 The Government's aim – set out in *Every Child Matters* – is that all children, whatever their circumstances, will have the support they need to:

- be healthy;
- stay safe;
- enjoy and achieve;
- make a positive contribution;
- achieve economic well-being.

6.5 These ambitions should apply to young carers, as they do to all other children.

6.6 This is right in itself. Security, health and having the time and space to learn are vital to every child's personal development and well-being. They are also essential given the economic and social changes now taking place. We live in an increasingly complex world. Skill expectations among employers are rising. All young people will need higher levels of educational achievement and a broader range of personal skills to succeed in life.

- 6.7** Young carers we spoke to during the consultation understand this. They do not want to stop caring altogether. But they do want a life – to study, to have time with friends and have the opportunities to progress as others do. The vision and outcomes we have set for young carers are designed to reflect that.
- 6.8** Our vision for 2018 is one in which professionals in our front-line services who are in most regular contact with young people have the knowledge they need to identify problems early and encourage young carers to come forward for the help they may need.
- 6.9** It is a vision where high quality targeted support is accessible to those who need it and based on sound evidence of what works.
- 6.10** Above all, it is one where prevention – protecting young people from falling into inappropriate caring – is the priority and a guiding principle behind the planning and delivery of services. Effective support for families and the person being cared for is at the heart of this. By 2018, our aim is that all areas will be delivering better joined-up, whole-family support to families affected by illness, disability or substance misuse who have young carers. Assessments and support offered will take proper account of the need to protect children from inappropriate caring while families and parents themselves will have a greater say in the shaping of services around them.
- 6.11** *Aiming high for children* states:
 “Preventing poor outcomes from arising in the first place benefits children, young people and families directly. In addition, failure to prevent problems impacts not only on the family but also society more widely...”⁴⁵

Universal services

- 6.12** Our universal services – schools, general practitioners, hospitals – have a vital role to play in young carers’ lives. The support, understanding and practical guidance young carers receive through these settings can make a significant difference to their lives. Where it is lacking, young carers say it adds substantially to the pressures and problems they face.

45 *Aiming high for children: supporting families*, HM Treasury and Department for Education and Skills, 2007

- 6.13** Over recent years, there have been a number of major new developments across schools designed to strengthen the wider support available to all pupils, ensure better home–family links, build emotional resilience and foster more inclusive and supportive environments.
- 6.14** Such programmes include the National Healthy Schools Programme; the Social and Emotional Aspects of Learning (SEAL) programme; parenting support; extended service schools; and substantially increased investments in support for emotional well-being and mental health linked to schools. New investments in personalised learning, information, advice and guidance, and the increased range of study options opening up for pupils at the secondary stage and broader developments connected with our commitment to support all young people to participate in some form of learning or training until at least 18 will also bring benefits for young carers. For many, the increased flexibility in the pacing and form of study is likely to prove particularly helpful.
- 6.15** Complementing these developments, our updated advice on bullying has made reference to young carers.⁴⁶ New summary guidance leaflets for schools and health settings have been made available by the Children’s Society’s Include Project,⁴⁷ supported by grant funding from the Department for Children, Schools and Families (DCSF).
- 6.16** Schools resources are also available through a range of other third sector organisations, including the Princess Royal Trust for Carers Professionals website – www.carers.org/professionals

⁴⁶ *Safe to learn*: embedding anti-bullying work in schools, available at www.teachernet.gov.uk/wholeschool

⁴⁷ *Information for teachers and school staff*: supporting pupils who are young carers and *Information for healthcare professionals*: supporting young carers and their families, Children’s Society, available at www.youngcarer.com

FACTBOX

Young carers and education

Research indicates that as many as 27 per cent of young carers of secondary school age are experiencing problems in attending and achieving at school. For young carers in families affected by substance misuse, the problems are particularly acute, with 40 per cent experiencing educational difficulties.⁴⁸

- 6.17** There is, however, more to be done. Schools can be a vital source of support and welcome contact with peers but many young carers feel that the issues and challenges they face are not always understood. Too often, young carers feel they need to keep their status hidden, even from their closest friends. Some do so out of fear of being seen as different – many young carers have highlighted they feel that stigma is still attached to disability and illness. Some do so because they see family matters as private. Others – possibly those in greatest need – do so out of fear of social services’ intervention. For many young carers, the resulting isolation and the lack of someone to talk to are particular problems. Opportunities to pick up on problems early are also being missed.
- 6.18** The major new support programmes now rolling out across our schools provide vital new opportunities for young carers’ issues to be addressed. The National Healthy Schools Programme, in particular, provides a framework for schools to develop positive, inclusive environments which actively promote and support the health and well-being of pupils and staff alike. For young carers, these developing opportunities have yet to be fully exploited. We want to ensure that they are and that all schools have the wider support and resources they need to take better account of young carers.
- 6.19 New commitment:** Over the coming three years, we will invest in a new programme of work to embed support and guidance on young carers through our National Healthy Schools Programme and to ensure tailored and up-to-date resources are available for staff to draw upon as

48 Dearden and Becker, *Young Carers in the UK: The 2004 Report*, 2004

part of their SEAL and Personal, Social, Health and Economic education (PSHE) programmes. We will work with Teachers TV to ensure future programmes aimed at school staff capture the invaluable testimony and experiences of young carers gleaned through the consultation.

- 6.20** Furthermore, we will liaise with the new further education improvement body to ensure that learning from developments across schools informs approaches across colleges and other further education settings. We will also work closely with the Children's Workforce Development Council and the Training and Development Agency to ensure that the new resources made available inform future developments in training for school staff and everyone who works with children.

"Schools need to ensure teachers are offered training on young carers and disability issues both at university and on inset days." (Young carer speaking at Young Carers Festival 2006)

- 6.21 New commitment:** We will also provide funding to support broader awareness-raising across schools and other children's settings on caring in families and the issues this raises.

"Schools need to recognise that our responsibility as carers can affect our education and schoolwork." (Young carer speaking at Young Carers Festival 2006)

- 6.22** Across our health settings, there is also more to be done. Like adult carers, young carers need clear and timely information to support them in their caring role but as children they also have distinct needs. We want to ensure key healthcare professionals have the knowledge and confidence to address these.

- 6.23 New commitment:** Over the next two years, we will fund the development of tailored training materials to be used with GPs and hospital discharge teams, complementing the broader investments in training and awareness-raising planned for GPs and other health staff in this strategy. Our aim is to ensure we offer the best possible support to staff in these key settings, helping them to take better account of young carers' needs as children and as carers.

Targeted support for young carers

6.24 Since the publication of *Caring about Carers*, targeted support for young carers has grown. The number of dedicated young carers' projects and services across the UK – the majority third-sector led – has increased from 110 in 1999 to some 350 currently.⁴⁹ These projects are in contact with around 25,000 young carers. In England, third sector organisations report that projects are supporting around 22,000 young carers.

Online support for young carers

www.youngcarers.net, or 'YcNet' is a national online support service for young carers across the UK. Run by The Princess Royal Trust for Carers, YcNet provides support and information to young carers under the age of 19 who may otherwise have remained hidden. Staffed by qualified youth workers, YcNet provides support to young carers through moderated discussion boards, agony aunt pages, a moderated chatroom, 1-1 online chats with workers, blogs by young carers and information on a wide range of issues relevant to young carers. One service user said this about the site: "I really enjoy getting the chance to talk to other young carers about the things that I want to talk about, everyone has an understanding of what you're going through which makes it so much easier."

CASE STUDY

6.25 Tailored support is also available through a range of other local services including targeted youth support, and more specialist services including child and adolescent mental health services.

6.26 Funding and other measures have contributed to this expansion in targeted services. The Vulnerable Children Grant (now mainstreamed), the Carers Grant and investments via the third sector to help build capacity and promote good practice among staff in front-line settings have all played their part.

49 'Global Perspectives on Children's Unpaid Caregiving in the Family', *Global Social Policy*, Vol. 7

- 6.27** Complementing the expansion in face-to-face and project-based support, the new national carers' helpline, due to go live in spring 2009, will include a specially tailored service for young carers. This will provide young carers with an easy-to-access source of information with signposting to other more specialist sources of support.

Young carers supporting and helping other young carers

Minds, Myths and Me is a fact pack for young carers (aged 12+) who live with someone with a mental illness. This A5 booklet was designed and produced by four young carers in Gloucestershire, using their own experiences to help others in the same situation.

**CASE
STUDY**

- 6.28** Young carers speak particularly highly of the project-based support they receive. Many value the social and support activities projects provide and the opportunity they offer to get a break and mix with other young carers.
- 6.29** The form of support that projects offer varies significantly across the country. A number provide group activities coupled with more intensive forms of support including access to counselling and short breaks at residential centres. Some projects have developed whole-family working using multi-agency teams drawn from social, education, health and parenting support services.

Young Carers SPACE Project

The SPACE project was developed by Hillingdon Carers to give support to young people caring for a family member affected by substance misuse and to prevent family breakdown – 86 young people were supported by this project in 2007/08.

SPACE shows the impact that whole-family, multi-agency services can have on young people with complex needs. It works with all the organisations and agencies in contact with a young person's family and rather than treat one problem or one family member in isolation, it brings together schools, the youth justice system, parenting support, the health service and others, addressing problems and families in the round. By understanding this wider context, and working towards a truly multi-agency response, SPACE engages young carers facing complex challenges with support that meets their needs.

CASE STUDY

- 6.30** Many projects are seen to offer excellent support and are a vital lifeline for young carers but a detailed evaluation of the different approaches and their impact on young carers and their outcomes is lacking.
- 6.31 New commitment:** Over this coming year, we will commission further research to assess the different approaches and forms of targeted and project-based support available and to capture and distil best practice. We will also examine where caring may bring particular disadvantages for particular groups of young people and review approaches to address that. We will ensure the learning from this research is shared across all areas so provision continues to grow in quality and impact.
- 6.32** However, the pattern and shape of local provision is changing. New developments including extended schools, targeted youth support and the broader array of investments to increase young people's access to positive activities offer important new opportunities for young people to access the support and broader recreational opportunities they need.

6.33 New commitment: To ensure we capitalise on these opportunities for young carers, we will invest in a new programme of work to ensure that the learning we draw from existing young carers' projects and other forms of support feeds into and helps shape the planning of provision across these newer settings and programmes. Our Extended Schools and Targeted Youth Support developments will be particular priorities. Our aim from this work is to ensure that young carers get the best possible access to, and benefit from, the new developments and that local areas are able to strengthen the range and quality of support they make available to meet young carers' needs.

National Young Carers Forum

The Children's Society, in partnership with the Princess Royal Trust for Carers, have supported the development of the first National Young Carers Forum for England. Members of the Forum have made a DVD called *Listening to Young Carers*, in which the young people talk about the issues they face and share solutions that will help improve their lives. The footage offers powerful insights into how young carers feel and the issues they face.

The footage will be used in a specially targeted programme of training for professionals working with young carers and their families.

CASE STUDY

Whole-family support

6.34 Young carers from across England have had a major input into the consultation. Over 100 ideas for change and improvement were put forward as part of the large-scale consultative event for young carers held in June 2007. Projects across the country completed the ideas tree and a specially tailored deliberative event attended by 26 young carers, project leaders and others was held in November 2007.

- 6.35** Young carers were asked what changes would make the greatest difference in their lives. While a number of different ideas emerged throughout the course of the consultation, it was consistently the need for better support for the family and the person cared for which emerged as the top priority.
- 6.36** Young carers expressed particular concerns about the lack of high-quality and reliable support for the person they care for. Many felt they had no choice other than to step in to fill the gap. They called for better access to equipment and for cover in emergencies when usual care arrangements break down. They asked for more support for parents to be parents, for the family to be a family, and for support to give them the time and space they need.

How gaps in the join up of support can impact on young carers

John's Mum, Jackie, had a stroke and lost mobility. John (13) was caring for Mum including helping her with intimate care such as using the toilet during the night, as well as a wide range of household tasks and looking after his younger sister. This provision of care, particularly of intimate care, resulted in a deteriorating parent-child relationship, tiredness and behavioural difficulties in school. He was the victim of bullying related to negative perceptions of his Mum and was also taking out frustration in aggressive behaviour of his own. The intervention needed to prevent John's excessive caring role was identified as night-support for Jackie. But Jackie did not qualify for night-support from adults services in her own right, whilst children's services felt they could not fund night support for an adult, so the services debated who should pay while John carried on caring. This situation persisted, with increasing impacts on John's school attendance, until Jackie eventually recovered enough to move herself at night.

CASE STUDY

6.37 We have introduced a range of measures to strengthen general support for families. We have done so by integrating children’s services through the *Every Child Matters* agenda and by strengthening financial support to families on low incomes. We have also done so through other more targeted measures, at the heart of which is new support for better whole-family working.

FACTBOX

Every Child Matters – Integrated Children’s Services

Every Child Matters (ECM): Change for Children set out an ambition to improve well-being for every child, whatever their background or their circumstances, and to have the support they need to:

- be healthy;
- stay safe;
- enjoy and achieve;
- make a positive contribution;
- achieve economic well-being.

ECM has driven integration in children’s services and better partnership working at all levels – through inter-agency governance and integrated strategy, processes and front-line working. Local areas have made significant progress in implementing these reforms:

- all local authorities have appointed or are in the process of appointing a Director of Children’s Services and have designated a Lead Members for Children’s Services;
- the national outcomes framework for children has been embedded across children’s services;
- 140 local areas are using both the Common Assessment Framework and lead professionals – on course for all areas by the end of 2008;
- over 8,000 Extended Schools are already in place.

- 6.38** We have invested £16 million in a new Family Pathfinder programme which will run in 15 selected local authority areas over the next three years. The funding includes £3 million for an extended Family Pathfinder programme, which will be used by six of the local authorities to look specifically and in greater depth at how to build better, more preventative forms of support around families at risk of relying on the care of a child. The prime aim is to develop models of support which will protect young carers from falling into inappropriate caring in the first place. The Extended Family Pathfinders for young carers will deliver vital learning which will be shared across all local areas over the next three years.
- 6.39** We have provided £600,000 over the three years to 2010 to the Children's Society and the Princess Royal Trust for Carers to develop new, broad-based guidance on whole-family working/good practice principles in relation to young carers. Over the coming two years, training based on the guidance will be provided for one local authority in every region. Three national road shows are also planned to enable other local authority and third sector services to access the training. Both the Good Practice Principles and the "Whole Family Pathway", which is an electronic resource, are available at www.youngcarer.com
- 6.40** As part of our Aiming high for disabled children programme, over the period 2008–11 we have also invested £370 million together with new growth funding included in Primary Care Trust baseline allocations, to increase support and short breaks to families with disabled children. This significant strengthening of support for families with disabled children will bring benefits for the whole family including any siblings in those families who assist with caring. The 2004 Dearden and Becker survey of young carers suggests that some 30 per cent are undertaking caring because of a disabled or sick sibling in the family.
- 6.41** A range of new measures have been introduced to strengthen parenting support, which will bring benefits for all parents, including those affected by long-term illness or disability. Particularly relevant is the Parenting Implementation Project which, in 2008–09, will include piloting new ways of reaching and supporting vulnerable or hard-to-reach parents, including parents with disabilities whose children may be young carers. We have also recently placed family support and the needs of dependent children at the heart of our new drugs strategy.⁵⁰

50 *Drugs: protecting families and communities*, HM Government, 2008

FACTBOX

Drugs Strategy

<http://drugs.homeoffice.gov.uk/drug-strategy/>

We recognise that children and young people in families affected by substance misuse face particular challenges. Some risk falling into inappropriate caring roles. As our new Drugs Strategy sets out, we are committed to ensuring that the welfare of these children is protected and that they are able to access appropriate support.

To achieve this vision:

- **Carers services need to proactively engage** carers in families affected by substance misuse.
- **Substance misuse services** must recognise the importance of whole family working and take account of the need to protect children from inappropriate caring and levels of responsibility.
- **Mainstream children's services need to be equipped to spot the symptoms of substance misuse** in a child's family.

The commitments in this strategy – including further research into the patterns of support needs in families with young carers – reinforce those in the Drugs Strategy. Together they will help to achieve our commitment that **all** young carers, including those caring as a result of substance misuse, receive the support they need.

6.42 All these measures together provide a significant new platform for progress and many local services are already innovating and adapting services around whole-family principles. But too many young carers are still shouldering significant responsibilities or undertaking caring of a type which is inappropriate for their age. Too many are reaching projects and accessing support only when problems are well-established, and in some cases deeply entrenched. We need further, focused action to help change this.

6.43 New commitment: To accelerate the pace of systems change and help more local areas shift their support for families with young

carers towards active prevention, we will expand our Extended Family Pathfinders for Young Carers programme. We will invest an additional £4 million over the two-year period 2009/10–2010/11, enabling up to a further 12–13 local areas to participate in the programme. This will significantly increase the reach and impact of the programme, ensuring that knowledge and expertise is shared more quickly across all regions. The original programme attracted large numbers of applications from local areas that are clearly keen to achieve progress and improvement for young carers and their families. This new investment will enable many more to do so. It will ensure that there are centres of practical knowledge and expertise on which local areas in every region can build. It will provide a strong foundation on which to deliver the effective prevention and improved support around families with young carers that we need to see. Details of the selection processes for the new Pathfinder areas will be announced later in 2008.

- 6.44** We also want to ensure that the invaluable contribution currently being made by third sector young carer projects also feeds into, and directly supports, our prevention agenda.
- 6.45 New commitment:** Over the next two years, we will therefore make £1 million available to support new and innovative work by projects focused on lifting young carers out of excessive caring. We will look to projects bidding for funds to work closely with local authority and PCT-funded services that are already supporting the family, so that approaches can be carefully tailored to the needs of the whole family and improvements are genuinely sustainable. Mechanisms for delivering this funding will be announced later this year, following consultations with key third sector bodies.
- 6.46 New commitment:** Complementing this, additional funding will be invested in an expanded programme of local and regional training on whole-family working for staff in local services. Teams within adult mental health and substance misuse services will be particularly targeted, given evidence now available about the particular difficulties experienced by some young carers in families affected by mental health problems and substance misuse. This new investment will directly support commitments to strengthen support for families and protection for dependent children as part of the our new drugs strategy.

Keeping Family in Mind

Keeping the Family in Mind Resource Pack is aimed at anyone who works with parents with mental health problems, their children and their families. It is a multi-media package of training resources designed to raise awareness of the issues that families face. All the resources have been written and produced with the participation of young carers. It includes telling insights into how services can affect the lives of families.

Keeping the Family in Mind Resource Pack, Barnardos and CSIP www.barnardos.org.uk/resources/research_and_publications.htm.

CASE STUDY

6.47 The reasons why children fall into excessive or inappropriate caring are, however, rarely simple. We do not yet have a clear enough view of where the greatest gaps in support are, or the extent to which family or wider factors contribute to problems emerging. If services are to respond and more effective support is to be built early around families, we need to fill this knowledge gap. We need to know more about both the scale and nature of the problem.

6.48 New commitment: Over the coming year we intend, therefore, to commission further work to investigate the patterns of support needed in families affected by disability, illness and substance misuse. The work will review the evidence on the scale of inappropriate or excessive caring by children. It will examine where and to what extent further service change might be needed beyond 2011 to ensure children are better protected from inappropriate caring. The work will take account of the survey which the Commission of Social Care Inspection, with Ofsted involvement, is to conduct over this coming year into services for disabled parents, including those with young carers.

Longer-term measures

- 6.49** Over the next three years to 2011, our strategy will ensure that support and understanding for young carers and their needs is better embedded within our universal and targeted services. However, our overriding objective is to move our systems of support towards better prevention. The substantial new investments we are making in support of whole-family working reflect that.
- 6.50** Change in this area will take time. Over the longer term, we will need to consider what further measures may be needed to deliver on our vision and to ensure that protections for young carers and new ways of working around families are fully embedded.
- 6.51** The research we will commission later this year will play a vital role in informing the further measures we take. In light of that, we will consider:
- whether more formal levers, such as the introduction of a national performance indicator, should be included when reviewing the National Indicator Set as part of the next spending review;
 - what further specific services and support around the family might be needed.
- 6.52** Our strategy assumes that tailored support for young carers will continue to be important. However, our aim is that, over time, the need for more intensive remedial support for young carers should reduce as families are better supported and young carers themselves better protected. We want active prevention to be at the heart of our systems of support – delivering better outcomes for families as a whole and ensuring that all young carers are supported to be what they should be: children and young people first.

Short term: Commitments

Funding to embed support and guidance for young carers through our Healthy Schools Programme and to ensure tailored and up-to-date resources are available for staff to draw upon as part of their SEAL and PSHE programmes.

Funding to support broader awareness-raising across schools and other children's settings on caring in families and the issues this raises.

Tailored training materials to be used with GPs and hospital discharge teams to build awareness and skills in dealing with young carers.

Programme of work to ensure that the learning we draw from existing young carers projects and other forms of support feeds into, and helps shape, the planning of provision in the future.

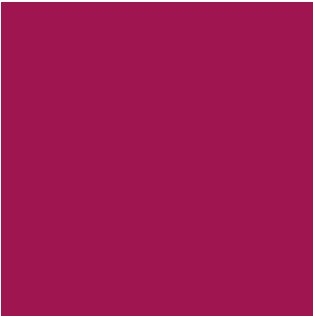
Preventing children from falling into harmful levels of caring: further action to build effective joined-up support around the family and the person cared for and to shift systems of support towards active prevention.

An expanded programme of local and regional training on whole-family working for staff in local services.

Longer term: Identified priorities

Ensuring protections for young carers are fully embedded: further measures to be considered in the light of research findings over the next two years.

Chapter 7: Implementation



Context

7.1 We need to make sure that robust arrangements are in place to help both us and our delivery partners to form a strategic overview of progress in taking forward this strategy. These arrangements need to fit within the new performance arrangements set out in the Local Government White Paper *Strong and Prosperous Communities*.⁵¹

Maintaining a strategic overview at national level

7.2 We need to maintain a strategic overview of the carers' agenda at a national level if we are to ensure progress on implementing the strategy. We will do this through a number of measures.

7.3 In December 2007, we established a Standing Commission on Carers (see Introduction). The Commission will play a key role in advising us on progress in implementing this strategy, including a specific overview on equalities issues, and will advise on ways that carers can be further supported in the light of longer-term demographic changes and the changing expectations of society. The Chair of the Commission will publish an annual report which will be shared widely.

7.4 We will also establish a programme board to complement the work of the Commission. The programme board will include senior representatives from across Government and key delivery partners. It will be responsible for ensuring that the necessary preparatory work is undertaken to support the delivery of the longer-term proposals contained in this document, as well as ensuring that the commitments made for the next two years are implemented.

7.5 Both the Commission and the programme board will be informed by the results of the carers' surveys detailed in this chapter, the findings of the pilots announced in the strategy, and other research evidence – for example, from the individual budget pilots for children and other key strategy documents such as the Care and Support Green Paper.

7.6 Together the evidence will provide a strong base, in terms of offering innovative and outcome-based solutions, for the commissioning of services for carers in the future.

51 *Strong and Prosperous Communities: The Local Government White Paper*, Department for Communities and Local Government, 2006

Maintaining a regional and local overview

- 7.7** Regional and local oversight of progress will take place within agreed performance frameworks. A number of new arrangements and mechanisms have recently been put in place, or are in train, that will strengthen the development of a multi-agency approach and partnership working and are particularly relevant in achieving delivery of this strategy. These are detailed throughout the chapter.

FACTBOX

Joint Strategic Needs Assessments and Local Area Agreements

A Joint Strategic Needs Assessment (JSNA) describes the future health, care and well-being needs of the local population. A Local Area Agreement (LAA) is an agreement between central government, local authorities and their partners on the priorities for a three-year period for improving services and the quality of life in a geographical area. Together they form a major part of the new local performance framework, which seeks to deliver better outcomes for service users and carers through more joined-up services.

Local performance framework

- 7.8** The Local Government and Public Involvement in Health Act (2007) changes the statutory landscape upon which the new local performance framework is founded. It places a number of duties on local authorities and PCTs – including a duty on them to undertake a JSNA of the health, care and well-being needs of the whole community. This will highlight the diversity of those using care services and their carers, and will identify the needs of those funding their own care or caring for people who are not eligible for statutory services. The JSNA will inform local commissioning strategies to ensure that the necessary services are in place or locally available.
- 7.9** The new local performance framework offers a major opportunity for carers to feature more prominently as a client group in their own right

and as part of the general social care user population. LAAs must be approved by ministers, and each LAA includes up to 35 priority targets selected from the National Indicator Set, which identifies the indicators to help measure priority outcomes. Local authorities and their partners can also agree additional local targets. The current indicator on carers (*NI 135 – Carers receiving needs assessment or review and a specific carer’s service, or advice and information*) is one of the most popular targets and it is identified as a priority in over half of LAAs in England.

- 7.10** Although NI 135 is a useful output measure and sends a powerful message about the priority we place on meeting carers’ needs, it does not give a clear enough indication of carers’ experience of the way that services are provided, and it counts only those carers who have received an assessment and service of some sort from their local authority.
- 7.11** As part of a wider review of social care indicators to be considered for inclusion in the next iteration of the National Indicator Set (which will be agreed through the next Spending Review), we will be reviewing the effect of the current carers’ indicator within the context of the aims and outcomes of this strategy. Where a need for further development is identified, we will consider options for creating a new outcome-focused indicator based on carers’ experience.
- 7.12** We will explore further options to measure carers’ experience of services in a shorter timeframe, during the current Spending Period. One option may be to include carers’ experience within the local authority survey programme for NI 127 (self-reported experience of social care users), as part of the work to develop proposals for populating this indicator.
- 7.13 New commitment:** To support this move towards greater measurement of carers’ experience of services, we are working with the Information Centre (a special health authority which provides facts and figures to help the NHS and social services run effectively) to develop a carer experience survey for local authorities to undertake on a voluntary basis in 2009–10.
- 7.14** This survey will provide both local authorities and central government with vital data on whether carers are receiving the services they need and what they think of the quality of those services. It will benefit local areas when commissioning services for carers, and will help to identify harder-to-reach groups who are currently not accessing services.

Improving data

- 7.15** The inclusion of a question about carers in the 2001 Census was a major achievement; it allowed data about carers to be collected down to a sub-ward level, providing reliable and tailored data sources with which local authorities and PCTs can plan services. The data can be used to make a number of comparisons between caring and poor health, for example, and between carers and BME communities. An example of the benefits of this data source can clearly be seen from the six reports released by Carers UK and Leeds University in 2007.⁵²
- 7.16** Although the 2001 Census provided vital information, stakeholder groups and academics both within and outside government have highlighted the lack of basic up-to-date data on carers; their overall numbers, the details of their caring role and the numbers of them in work, for example, as well as basic characteristics such as their age, gender, ethnicity, disability and health status.
- 7.17 New commitment:** Bearing in mind the concerns raised, we have secured additional funding to ensure that the question on carers is included in recommendations to Parliament for the 2011 Census. One of the major benefits of this is that it will provide a 10-year comparison with 2001 for the number of carers in each local area and the number of hours of care they provide.
- 7.18** Data and information about carers, over and above that provided by the Census, was provided between 1985 and 2000 by the General Household Survey.
- 7.19 New commitment:** In recognition of the importance of this information, the Government is committing to fund a module on carers in an Omnibus Survey in 2008–09. The module will contain a number of questions about carers and will be tailored around the strategy – going beyond the usual questions about carers and the health and social services they receive, it will ask questions about employment, income and housing.
- 7.20** This information will be vital for central and local government and the third sector, and will allow them to map service provision and commission services for better effect.

52 *Carers, Employment and Services Report Series*, Carers UK/University of Leeds, 2007

Putting people first – transformation process

7.21 As earlier chapters of this document make clear, the transformation of adult social care will require a shift to a more personalised, holistic approach to care and support. We need to work with family members and other carers as partners to make sure that support solutions address the needs of all those involved, and that they help carers to develop their skills and confidence. Over the next three years we will provide £520 million through the Social Care Reform Grant to support councils to redesign their systems so they can deliver this transformation.⁵³

7.22 Key elements of this transformation process of specific relevance to carers and carers' organisations include:

- a new skills academy to improve the commissioning of services and leadership in social care, and local workforce development strategies to raise skills levels;
- the development of forums, networks and task groups, actively involving people who use services and their carers, to design and oversee the change to a personalised system;
- support for third sector innovation and social enterprise.

7.23 This transformation will be delivered by local partners working together through the new local performance framework outlined above and through local leadership and regional leadership. Organisations working together to achieve transformational change will include:

- the Association of Directors of Adult Social Services;
- the Association of Directors of Children's Services;
- the Local Government Association;
- the NHS Confederation;
- the Care Services Improvement Partnership;
- the Care Services Efficiency Directorate;
- the Improvement and Development Agency for Local Government (IDeA).

7.24 The strengthened role of the Department of Health in the regions, together with the Regional Improvement and Efficiency Partnerships, will have a key role in supporting improvement locally and co-ordinating support with Joint Improvement Partnerships and other relevant organisations including IDeA.

Assessment and regulation

7.25 Subject to the enactment of the Health and Social Care Bill, an integrated regulator for health and social care – the Care Quality Commission – will be created to replace the Healthcare Commission, the Commission for Social Care Inspection and the Mental Health Act Commission. We believe strongly in the importance of engaging the public, people who use services and carers in the work of the Care Quality Commission, and recognise the good work that the existing commissions have done in this area.

7.26 A new independent assessment and inspectorate regime, Comprehensive Area Assessment, will be introduced from April 2009. This will put greater focus on the public's experiences and perspectives than has hitherto been the case.

Short term: Commitments

Establishment of a 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 term: Identified priorities

Review of the National Indicator Set to ensure that carers' experience of services is measured.

Annex A: *Putting People First*





Putting People First

A shared vision and commitment
to the transformation of
Adult Social Care



Putting People First

A shared vision and commitment to the transformation of Adult Social Care

I Introduction

The Our health, our care, our say White Paper and statements in the 2007 budget report and Comprehensive Spending Review announcement outlined the key elements of a reformed adult social care system in England; a system able to respond to the demographic challenges presented by an ageing society and the rising expectations of those who depend on social care for their quality of life and capacity to have full and purposeful lives.

Demography means an increasing number of people are living longer, but with more complex conditions such as dementia and chronic illnesses. By 2022, 20% of the English population will be over 65. By 2027, the number of over 85 year-olds will have increased by 60 %. People want, and have a right to expect, services with dignity and respect at their heart. Older people, disabled people and people with mental health problems demand equality of citizenship in every aspect of their lives, from housing to employment to leisure. The vast majority of people want to live in their own homes for as long as possible.

In the context of changing family structures, caring responsibilities will impact on an increasing number of citizens. Examples include an eighty-year-old woman having to cope with her husband's dementia, a young mum pursuing a career and bringing up a family while looking after her elderly parent, a business executive working overseas whose widowed mother is hospitalised overnight following a stroke and older parents seeking for the right support to ensure their adult son with a learning disability can live independently.

We agree that there is a need to explore options for the long term funding of the care and support system, to ensure that it is fair, sustainable and unambiguous about the respective responsibilities of the state, family and individual. As stated in the Comprehensive Spending Review (CSR) announcement 2007, the Government will produce a Green Paper following extensive public consultation setting out the key issues and options for reform. Notwithstanding the Green Paper on longer-term reform of the funding system and following the recent CSR settlement, there is now an urgent need to begin the development of a new adult care system. A personalised system which can meet the challenges described earlier and is on the side of the people needing services and their carers. While acknowledging the Community Care legislation of the 1990s was well intentioned, it has led to a system which can be over complex and too often fails to respond to people's needs and expectations.

This landmark protocol seeks to set out and support the Government's commitment to independent living for all adults. It also outlines the shared aims and values, which will guide the transformation of adult social care. It is unique in establishing a collaborative approach between central and local Government, the sector's professional leadership, providers and the regulator. It seeks to be the first public service reform programme which is co-produced, co-developed, co-evaluated and recognises that real change will only be achieved through the participation of users and carers at every stage. It recognises that sustainable and meaningful change depends significantly on our capacity to empower people who use services and to win the hearts and minds of all stakeholders', especially front line staff. Local government will need to spend some existing resources differently and the Government will provide specific funding to support system-wide transformation through the Social Care Reform Grant, in line with agreements on new burdens.

We do not seek to prescribe uniform systems and structures in every part of the country. However, access to high quality support should be universal and available in every community. Some of these reforms can be made within the parameters of the local adult social care policies. Others require adult social care to take a leadership role within local authorities, across public services and in local communities.

Ultimately, every locality should seek to have a single community based support system focussed on the health and wellbeing of the local population. Binding together local Government, primary care, community based health provision, public health, social care and the wider issues of housing, employment, benefits advice and education/training.

This will not require structural changes, but organisations coming together to re-design local systems around the needs of citizens. The new local performance framework, which covers the delivery of all services by local government working alone or in partnership, will help to create an improved approach to local partnership, enabling local authorities and partners to work together to lead their area and better meet the public's needs. The transformation of adult social care will be delivered through the new performance framework, and will draw on new mechanisms within the framework, such as the new statutory requirement on local authorities and PCTs to undertake a Joint Strategic Needs Assessment, to ensure that the transformation process really delivers on the challenges for each local area.

In future organisations will be expected to put citizens at the heart of a reformed system. Incentives will include the new focus of the local performance framework, guidance on commissioning for health and wellbeing, Human Rights legislation, and any international obligations such as the new UN Convention on the Rights of Persons with Disabilities.

2 Values

Ensuring older people, people with chronic conditions, disabled people and people with mental health problems have the best possible quality of life and the equality of independent living is fundamental to a socially just society.

For many, social care is the support which helps to make this a reality and may either be the only non-family intervention or one element of a wider support package.

The time has now come to build on best practice and replace paternalistic, reactive care of variable quality with a mainstream system focussed on prevention, early intervention, enablement, and high quality personally tailored services. In the future, we want people to have maximum choice, control and power over the support services they receive.

We will always fulfil our responsibility to provide care and protection for those who through their illness or disability are genuinely unable to express needs and wants or exercise control. However, the right to self-determination will be at the heart of a reformed system only constrained by the realities of finite resources and levels of protection, which should be responsible but not risk averse.

Over time, people who use social care services and their families will increasingly shape and commission their own services. Personal Budgets will ensure people receiving public funding use available resources to choose their own support services – a right previously available only to self-funders. The state and statutory agencies will have a different not lesser role – more active and enabling, less controlling.

3 A personalised Adult Social Care System

The key elements will be:

3.1 Local authority leadership accompanied by authentic partnership working with the local NHS, other statutory agencies, third and private sector providers, users and carers and the wider local community to create a new, high quality care system which is fair, accessible and responsive to the individual needs of those who use services and their carers.

The current Darzi review of the NHS has recognised the relationship between health, social care and wider community services will be integral to the creation of a truly personalised care system.

3.2 Agreed and shared outcomes which should ensure people, irrespective of illness or disability, are supported to:

- live independently;
- stay healthy and recover quickly from illness;
- exercise maximum control over their own life and where appropriate the lives of their family members;
- sustain a family unit which avoids children being required to take on inappropriate caring roles;
- participate as active and equal citizens, both economically and socially;

- have the best possible quality of life, irrespective of illness or disability;
- retain maximum dignity and respect.

3.3 System-wide transformation, developed and owned by local partners covering the following objectives:

- A joint strategic needs assessment undertaken by local authorities, relevant PCT and NHS providers. This should be undertaken in conjunction with other local needs assessments and plans (for example, local housing strategies). The joint strategic needs assessment and these other plans will inform the Sustainable Community Strategy. It will also be accompanied by an integrated approach with local NHS commissioners and providers to achieve specific outcomes on issues including:
 - relevant preventative public health policies, e.g. infection control and fall reduction strategies;
 - hospital discharge arrangements;
 - the provision of adequate intermediate care;
 - the management of long term conditions;
 - packages of support with a health and/or nursing care element;
 - co-located services, bringing together social care, primary care and other relevant professionals;
 - community equipment services;
 - universal information, advice and advocacy;
 - carer support and public/patient involvement;
 - complaints systems.
 The full range of relevant local statutory, voluntary and private sector organisations need to be fully engaged. Where appropriate, Local Area Agreements will be the vehicle to bring together national policy with local priorities, informed by the vision developed by local partners. This will mean organisations being willing to allocate funding to others, if this will have greater impact on shared outcomes. The NHS Operating Framework will reflect a new shared responsibility for the health and wellbeing of citizens, families and communities.
- Commissioning which incentivises and stimulates quality provision offering high standards of care, dignity and maximum choice and control for service users.

Supports third/private sector innovation, including social enterprise and where appropriate is undertaken jointly with the NHS and other statutory agencies eg Learning and Skills Council, employment services, and Housing Authorities. This must be shaped by the Joint Strategic Needs Assessment.

- A locally agreed approach, which informs the Sustainable Community Strategy, utilising all relevant community resources especially the voluntary sector so that prevention, early intervention and enablement become the norm. Supporting people to remain in their own homes for as long as possible. The alleviation of loneliness and isolation to be a major priority. Citizens live independently but are not independent; they are interdependent on family members, work colleagues, friends and social networks.
- A universal information, advice and advocacy service for people needing services and their carers irrespective of their eligibility for public funding. A 'first shop stop', which could be accessed by phone, letter, e-mail, internet or at accessible community locations. Key strategic partners to be the Pensions Agency and relevant voluntary organisations. The LinkAge Plus pilots are providing strong evidence of the benefits for older people of this approach. Personal advocates to be available in the absence of a carer or in circumstances where people require support to articulate their needs and/or utilise the personal budget.
- A common assessment process of individual social care needs with a greater emphasis on self-assessment. Social workers spending less time on assessment and more on support, brokerage and advocacy.
- Person centred planning and self directed support to become mainstream and define individually tailored support packages. Tele-care to be viewed as integral not marginal.
- Personal budgets for everyone eligible for publicly funded adult social care support other than in circumstances where people require emergency access to provision. Lord Darzi's recent NHS next stage review interim report suggested that in the future personal budgets for people with long-term conditions could include NHS resources.

- Direct payments utilised by increasing numbers of people, as defined by locally set targets in LAAs.
- Family members and carers to be treated as experts and care partners other than in circumstances where their views and aspirations are at odds with the person using the service or they are seeking to deny a family member the chance to experience maximum choice and control over their own life. Programmes to be supported which enable carers to develop their skills and confidence.
- A transformed community equipment service, consistent with the retail market model.
- Systems which support integrated working with children's services, including transition planning and parent carers, and identifying and addressing concerns about children's welfare.
- Support for at least one local user led organisation and mainstream mechanisms to develop networks which ensure people using services and their families have a collective voice, influencing policy and provision.
- Systems which act on and minimise the risk of abuse and neglect of vulnerable adults, supported by a network of "champions", including volunteers and professionals, promoting dignity in local care services.
- Local workforce development strategies focussed on raising skill levels and providing career development opportunities across all sectors. Strategies to be co-produced, co-developed and co-evaluated with the private and voluntary sectors.

Adult social care will also take responsibility for championing the rights and needs of older people, disabled people, people with mental health needs and carers within the local authority, across public services and in the wider community. Early priorities will be intergenerational programmes involving older people as active citizens, integrated policy development which supports independent living (housing, access to work, education/training and leisure) including transition planning for young disabled people and local action to tackle the stigma faced by people with mental health problems.

4 Support for Reform

The Department of Health will provide funding over the next three years to support system-wide transformation in every local authority. Local authorities and their partners will agree together how this funding will be spent to develop the personalised system described in Section 3.

A detailed prospectus consistent with our core principles will be published in December.

In line with the soon to be published National Improvement and Efficiency Strategy (NIES), Department of Health (DH), will refocus the relevant activities of Care Services Efficiency Delivery Programme (CSED) and Care Services Improvement Partnership (CSIP) and seek partnerships with Regional Improvement and Efficiency Partnerships, local consortia, In Control and other 'change agents' to ensure every local authority has access to high quality support for the necessary change programme.

DH, and where appropriate, other Government Departments, will ensure new capital investment supports a more integrated approach to health and wellbeing in every community.

DH will lead a new cross-ministerial group including the Treasury, Department for Communities and Local Government (CLG), Department for Work and Pensions (DWP), Department for Innovation, Universities and Skills (DIUS) and Department for Children, Schools and Families to ensure a joined-up approach to adult social care transformation and the review of long-term funding. The need for legislative and regulatory changes will be considered in consultation with local Government, providers and other stakeholders.

A new skills academy is being developed with partners to support world class commissioning and leadership in social care. Skills for Care and the General Social Care Council (GSCC) will provide leadership to ensure entry level training, continued professional development and workforce registration to reflect the new skills required in a personalised system. In taking this forward, we will ensure that opportunities for co-ordination and joint capacity building are exploited with the World Class Commissioning programme for PCTs and those programmes in Children's services and the rest of local government. DH will also work with CLG and the Local Government Association (LGA) to consider how best to take this forward in the context of the NIES.

Social Care Institute for Excellence (SCIE) will be expected to promote, identify, and disseminate best practice and innovation, acting as a catalyst for system-wide transformation. Commission for Social Care Inspection (CSCI) and their successor regulator will align their approach to inspection and regulation with the reform agenda, in the context of the Comprehensive Area Assessment (CAA).

5 Timescale

Every local transformation process will include clear benchmarks, timescales and designated delivery responsibilities.

By the end of the CSR period in March 2011, we expect people who use services and their carers as well as front line staff and providers to experience significant progress in all local authority areas. Incremental progress should be evident over a shorter period of time.

6 Engagement/ Consultation

If we are to win the hearts and minds of all stakeholders, especially frontline staff, it is essential that they are participants in the change programme from the design stage onwards.

It is hoped that every local authority will create forums, networks and task groups which involve staff across all sectors, people who use services and carers as active participants in the change process.

7 Conclusion

We recognise that organisations such as In Control, other voluntary organisations and some local authorities have been at the cutting edge of innovation in adult social care for some time. The Individual Budget, Partnerships for Older People and LinkAge Plus pilots have begun to demonstrate what works as well as identifying barriers to progress.

However, national and local leadership is now essential if we are to achieve system-wide transformation. This is necessary because of demographic realities, but driven by a shared commitment to social justice.

This protocol seeks to be a catalyst – not a straightjacket – for innovation and is the first stage in a unique attempt to co-produce, co-develop and co-evaluate a major public service reform.

We will judge our success through the views and experiences of those who use the social care system, progress in supporting adults to live independently, objective measures of performance, and the job satisfaction of those working at all levels of the system.

In the future, adult social care will touch the lives of an increasing number of families.

By signing this historic protocol, we accept our shared responsibility to create a high quality, personalised system which offers people the highest standards of professional expertise, care, dignity, maximum control and self determination.



Secretary of State for Health



Chief Executive, NHS Confederation



Secretary of State for Work and Pensions



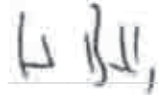
Chair, Society of Local Authority Chief Executives



Secretary of State for Communities and Local Government



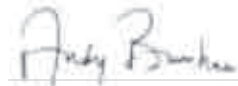
Chair, Commission for Social Care Inspection



Secretary of State for Children, Schools and Families



Chair, Social Care Institute for Excellence



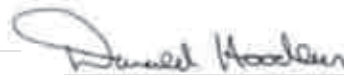
Chief Secretary to the Treasury



Chair General Social Care Council



Secretary of State for Innovation, Universities and Skills



Chair Skills for Care



Leader, Local Government Association



English Community Care Association



President, Association of Directors of Adult Social Services



National Care Association



Chief Executive, NHS



UK Home Care Association



Executive Director, National Care Forum

Annex B: About the consultation



In February 2007, we announced “the most far-reaching consultation on the future of carers ever” to identify the most significant issues in the journey to improve lives of carers in Britain today.

The public consultation was made up of a number of parts. A web-based “ideas tree” on which carers were invited to make proposals for improvements to the care and support that they receive. The ideas tree also sought comments on the proposals that had been put forward, meaning that during analysis it was possible to identify the proposals that had been rated the most important by carers.

Organisations were also encouraged to hold consultations, and were provided with a paper version of the ideas tree and a toolkit to facilitate their smooth running and effectiveness. Opinion Leader, the organisation contracted to undertake the research, received and analysed the results. The aim of this approach was both to raise carers’ awareness of the consultation and to increase their participation in this vital exercise. It ensured that those carers who were not able to access the web were still able to contribute their views.

Nine regional events, run by the Department of Health, explored carers’ attitudes and opinions in certain key areas, such as health and social care, income, employment and equalities. We ran a separate consultation for young carers to ensure their voices and views were heard.

The period of consultation lasted for six months. In November 2007, Opinion Leader held three deliberative events, two for adult carers and one for young carers, to test emerging themes with a large group of carers, professionals and members of the public.

The consultation concluded with a final consultative event in January 2008 which was attended by the Prime Minister, the Secretary of State for Health and the Minister for Care Services.

Overall, the consultation received the views of over 4,000 carers.

Annex C: Interdepartmental Group and Task Force membership



Interdepartmental group

David Behan (Chair)	Department of Health (DH)
Gary Belfield	DH
Raghuv Bhasin	DH
Louise Bridson	Department for Children, Schools and Families (DCSF)
Bruce Calderwood	Department for Work and Pensions (DWP)
Emily Cattell/Tracey Boscott	Government Equalities Office (GEO) (sharing role)
Norman Cockett	DWP
Sheila Dent/Alex Fox	Princess Royal Trust for Carers (sharing role)
Grant Ferres	DWP
Jenny Frank/Bob Reitemeier	Children's Society (sharing role)
Shane Hayward-Giles	DH
Mark Jarvis	Department of Innovation Universities and Skills
Caroline Marsh	Association of Directors of Adult Social Services
Alan Martin/Julie McLynch	Business Enterprise and Regulatory Reform (sharing role)
Craig Muir	DH
Julian Oliver	DH
Gavin Parry	Welsh Assembly
Jonathan Portes	DWP
Imelda Redmond	Carers UK
Anne Roberts	Crossroads
Geoff Scammell	DWP
Janice Shersby	GEO
Peter Stapleton	Scottish Executive
Richard Taunt	Her Majesty's Treasury (HMT)
Sam Whittaker	HMT

Employment Task Force members

Jonathan Portes (co-chair)	Department for Work and Pensions (DWP)
Caroline Waters (co-chair)	British Telecommunications
Stephen Burke	Counsel and Care
Jane Burt	Princess Royal Trust for Carers
Angela Cannon	Department of Health (DH)
Alison Durbin	DWP
Richard Excell/ Sarah Veale	Trades Union Congress (sharing role)
Grant Ferres	DWP
Kate Groucutt	Carers UK
Rosemary Hawkins	Crossroads
Mark Jarvis	Department for Innovation, Universities and Skills
Olivia Knibbs	DWP
Julian Oliver	DH
Martin Payne/ Julie McLynchy	Department for Business, Enterprise and Regulatory Reform (sharing role)
Debbie Ralph	Jobcentre Plus
Geoff Scammell	DWP
Marion Seguret	Confederation of British Industries
John Skinner	DWP
Madeleine Starr	Action for Carers in Employment national programme
Sam Whittaker	Her Majesty's Treasury
Sue Yeandle	University of Leeds

Equalities Task Force members

Janice Shersby (co-chair)	Government Equalities Office (GEO)
Baroness Sally Greengross (co-chair)	Commissioner, Commission for Equality and Human Rights (CEHR)
John Bangs	Association of Directors of Adult Social Services (ADASS)
Christine Barnes	CEHR
Elaine Drage	(sharing role)
Peter Blackman	Afiya Trust
Nita Devabhai	(sharing role)
Tracey Boscott	GEO
Emily Cattell	GEO
Jane Rushton	(sharing role)
Jenny Frank	Children's Society
Marian Harrington	ADASS
Karl Kanadia	ADASS
Trish O'Flynn	Local Government Association (LGA)
Mark Robertson	Contact a Family
Madeleine Starr	ACE/Carers UK (sharing role)
Katherine Wilson	

Health and Social Care Task Force members

Craig Muir (co-chair)	Department of Health (DH)
Jo Webber (co-chair)	NHS Confederation
Graeme Betts	Association of Directors of Adult Social Services (ADASS)
Raghuv Bhasin	DH
Louise Boddington	DH
Louise Bridson	Department for Children, Schools and Families
Paul Cann	Help the Aged
Angela Cannon	DH
David Congdon	Mencap
Rekha Elasarapu	The Healthcare Commission
Clive Evers	Alzheimer's Society
Alex Fox	Princess Royal Trust for Carers
Jenny Frank	Children's Society
Jill Harrison	Contact a Family
Paul Jenkins	Rethink
Caroline Marsh	ADASS
Anne McDonald	LGA
Julian Oliver	DH
Natalie Pinnock-Hamilton	Afiya Trust
Clair Pyper	Association of Directors of Children's Services
Imelda Redmond	Carers UK
Anne Roberts	Crossroads
Mary Robertson	Care Services Improvement Partnership
Nalyni Shanmugasathan/ Raphael Wittenberg	DH (sharing role)
Richard Taunt	Her Majesty's Treasury
Geraldine Teggart	Commission for Social Care Inspection

Income Task Force members

Bruce Calderwood (co-chair)	Department for Work and Pensions (DWP)
Lisa Harker (co-chair)	Independent consultant
Robert Beasley	DWP
Joanne Bird	Union of Shop, Distributive and Allied Workers
Norman Cockett	DWP
Harry Cunniffe	DWP
Dr Angus Erskine	Social Security Advisory Committee
Grant Ferres	DWP
Jean French	Carers UK
Denis Fryer	DWP
Kate Groucutt	Carers UK
Emily Holzhausen	Carers UK
Marilyn Howard	DWP
Jonathan Langridge	Her Majesty's Revenue and Customs
Kate O'Reilly	Her Majesty's Treasury
Barry Robinson	DWP
Vanessa Stanislas	Disability Alliance
Liz Sutherland	DWP
Gary Vaux	Hertfordshire County Council
Sally West	Age Concern



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