

Carers rapid needs assessment

May 2016



**Brighton & Hove
City Council**

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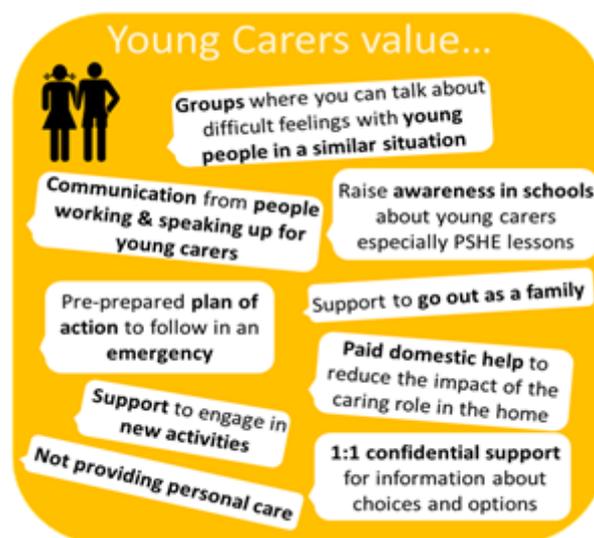
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1. Executive summary

- There are approximately 24,000 people providing unpaid care in Brighton & Hove.
- 8.8% of the population of Brighton & Hove identify as being a carer, which is lower than in the South East or England.
- Carers in Brighton & Hove are more likely to be female, 50-64 years old and from a White ethnic background.



- The wards with the highest percentage of carers are Woodingdean, Patcham and Hangleton and Knoll.
- The wards with the highest proportion of BME carers are Regency and Queen's Park.
- Carers accessing Adult Social Care services are more likely to be female and over the age of 65.
- Data from carers assessments showed that caring had an impact on many areas of carers lives, and that detrimental effects on 'undertaking leisure, cultural or spiritual activities', 'maintaining contact with people important to you' and 'getting out into the community' had the highest impact on wellbeing.
- Carers report that there is a risk of their mental health and physical health deteriorating due to their caring role and three quarters of carers have concerns about the longer term future.
- Around 65% of carers have one or more health conditions themselves.
- There are around 500-600 young carers in Brighton & Hove, around 50% of whom are between 11-13 years old.



- Compared with those who do not have caring responsibilities, young carers are
 - more likely to be from Black and Minority Ethnic groups and less likely to have English as their main language spoken at home
 - more likely to report harmful health behaviours such as smoking and drinking alcohol, and are more likely to have had sex, and at an earlier age
 - less likely to say they are happy, and are more likely to have felt miserable, angry and afraid
 - more likely to have problems at school such as attendance issues, bullying and exclusion
- Evidence from this needs assessment suggests a number of groups of carers either have higher needs, are at higher risk or are part of a group that services feel more information is needed about; these included young carers, parent carers, carers of people with drug and alcohol dependency or mental health problems and armed forces carers.

2. Introduction and background

The majority of care in the UK is provided by family members, friends and relatives. Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner. The 2011 Census shows 5.8 million people provide unpaid care in England and Wales, representing over one tenth of the population (10.3%).¹ The economic value of the contribution of carers in the UK is now £132 billion per year - close to the annual cost of the total health spend in the UK.²

Between 2001 and 2011 the number of carers has grown by 600,000 with the largest increase being in people who care for more than 50 hours a week. Unpaid care has increased at a faster pace than population growth, and an ageing population and improved life expectancy for people with long term conditions and complex disabilities means people are caring for longer.

Carers have increasing rights under new legislation, through the Care and Support Act (2014) carers have equitable rights to those that they care for. The local authority, in partnership with health, has to ensure that there are appropriate services to support the wellbeing and needs of carers.

The 2011 Census shows that 23,967 people in Brighton & Hove identify as carers, which represents 9% of the population. In their report Valuing Carers 2015, Carers UK estimated the economic value of the contribution made by carers in the city to be £437 million per year.²

3. Scope of the needs assessment

This needs assessment was completed between October 2015 and February 2016, and was designed to be a rapid assessment of carers' needs in Brighton & Hove. The following methods were used:

- Analysis of data from routine data sources
- Analysis of local data from Adult Social Care and local surveys
- Feedback from stakeholders through an Expert Panel and Questionnaire.

Recommendations are listed at the end of the report in Section 9.

This needs assessment has a number of limitations which largely relate to the short time frame in which it was completed. Further data could have been included from health services such as primary care. Information could have been requested on some of the groups that there is little information about such as carers of those with mental health problems or substance misuse. Other limitations stemmed from the availability of data; for example Children's Service at Brighton & Hove City Council are unable to extract and collate data from their IT system which would provide further information on young carers accessing services in the city.

4. Analysis of routine data sources

4.1 Census 2011³

The latest census was conducted in 2011 and was designed to capture data on every household in England and Wales. The question asking about unpaid care was: 'Do you look after, or give help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill-health/disability or problems related to old age?'

Table 1 shows that of the 273,369 people living in Brighton & Hove 23,967 (8.8%) identified themselves as providing unpaid care. This is a lower proportion than in the South East (9.8%) or England (10.2%). The number of carers in the city has increased by 2,164 since 2001, although the overall proportion of carers has not changed. The largest increase in carers was seen in the group providing 20-49 hours of care (30.0%).

Table 1: Provision of unpaid care in 2011 and 2001 in Brighton & Hove, South East and England, by number of hours of care provided (Census 2011)

Provision of unpaid care								
	2011 Census				2001 Census		Change 2001 to 2011	
	Brighton & Hove		South East	England	Brighton & Hove			
	Number	%	%	%	Number	%	Number	%
All usual residents	273,369				247,817		25,552	10.3
Provides no unpaid care	249,402	91.2	90.2	89.8	226,014	91.2	23,388	10.3
All person providing unpaid care	23,967	8.8	9.8	10.2	21,803	8.8	2,164	9.9
Provides 1 to 19 hours	16,401	6.0	6.7	6.5	15,457	6.2	944	6.1
Provides 20-49 hours	2,850	1.0	1.1	1.4	2,192	0.9	658	30.0
Provides 50 or more hours	4,716	1.7	2.0	2.4	4,154	1.7	562	13.5



Table 2 shows that the largest proportion of carers are providing 1-19 hours or care a week (68.4%), although a significant number are providing 20-49 hours (11.9%) and more than 50 hours a week (19.7%). There are overall a larger number (and proportion) of females (11.5%) in the city providing unpaid care than males (8.2%). Males are more likely to provide 1-19 hours or 20-49 hours, whereas females are more likely to provide 50 or more hours of unpaid care a week.

Table 2: Provision of unpaid care in Brighton & Hove by gender and number of hours of care provided (Census 2011)

			Males		Females	
	Number	%	Number	%	Number	%
All usual residents	273,369		122,862		119,400	
All person providing unpaid care	23,967	8.8	10,094	8.2	13,703	11.5
Provides 1 to 19 hours	16,401	68.4	7,059	69.9	9,200	67.1
Provides 20-49 hours	2,850	11.9	1,224	12.1	1,610	11.7
Provides 50 or more hours	4,716	19.7	1,811	17.9	2,893	21.1

Table 3 shows that the proportion of the population providing unpaid care generally increases with age, with those aged 50-64 having the highest percentage (19.8%).

Most of young carers are delivering 1-19 hours a week, with those aged 65+ having the highest proportion delivering 50 or more hours of unpaid care a week (34.5%).



Table 3: Provision of unpaid care in Brighton & Hove by age and number of hours of care provided (Census 2011)

Age	All persons	All persons providing unpaid care		Provides 1 to 19 hours unpaid care a week		Provides 20 to 49 hours unpaid care a week		Provides 50 or more hours unpaid care a week	
		No.	%	No.	%	No.	%	No.	%
Age 0 to 15	44,345	543	1.2	456	84.0	53	9.8	34	6.3
Age 16 to 24	43,541	1,633	3.8	1,284	78.6	201	12.3	148	9.1
Age 25 to 34	44,957	2,343	5.2	1,622	69.2	334	14.3	387	16.5
Age 35 to 49	64,137	6,849	10.7	4,660	68.0	876	12.8	1,313	19.2
Age 50 to 64	40,697	8,072	19.8	5,904	73.1	897	11.1	1,271	15.7
Age 65+	35,692	4,527	12.7	2,475	54.7	489	10.8	1,563	34.5

Table 4 shows the provision of unpaid care by ethnicity. The ethnic group with the largest proportion of people identifying as carers is White British (9.4%), followed by those classified as Other (8.9%). Census information describes this group as being a mix of people from countries like Japan, the Philippines and the Arab world. When looking at the individual ethnic groups identified in the census, Gypsy or Irish Travellers, who are included under White Other, have the highest proportion of identified carers (15.7%), although this represents small numbers. Those in the Mixed group are most likely to be delivering 1-19 hours of care a week (71.5% of this group) and those in the Other grouping

are most likely to be delivering 50 or more hours of unpaid care (27.2%), particularly those in the Arab ethnic group. (30.4%).

Table 4: Provision of unpaid care in Brighton & Hove by ethnicity and number of hours of care provided (Census 2011)

Ethnicity ^a	All persons	All persons providing unpaid care (% of ethnic group providing care)		Percent age of total carers in each ethnic group	Provides 1 to 19 hours unpaid care a week (% of ethnic group providing 1 to 19 hours care)		Provides 20 to 49 hours unpaid care a week		Provides 50 or more hours unpaid care a week	
		No.	%		%	No.	%	No.	%	No.
White British	220,018	20,766	9.4	81.9	14,269	68.7	2,369	11.4	4,128	55.4
White Other	23,494	1,396	5.9	5.5	978	70.1	176	12.6	242	62.0
Mixed	10,408	513	4.9	3.8	367	71.5	63	12.3	83	54.2
Asian or Asian British	11,278	677	6.0	4.1	438	64.7	118	17.4	121	72.7
Black or Black British	4,188	262	6.3	1.5	169	64.5	47	17.9	46	58.7
Other	3,983	353	8.9	1.5	180	51.0	77	21.8	96	54.2

Asian or Asian British carers are the most likely group to report they are in good health (80.2%) followed by Black or Black British carers (7.1%). The group least likely to rate their health as good were those in the Other ethnicity category (69.4%). When looking only at those providing 50 or more hours of unpaid care, those who are Asian or Asian British largely still describe themselves as in good health (72.7%) with all other ethnic groups dropping to 54.2- 58.7%.

Table 5: Provision of unpaid care in Brighton & Hove by ethnicity and self-rated health status (Census 2011)

Ethnicity	All persons providing unpaid care	Carers who are in 'very good or good health'		Provides 50+ hours unpaid care a week & in 'very good or good health'	
		No.	%	No.	%
White British	20,766	15,124	72.8	2,285	55.4
White Other	1,396	1,068	76.5	150	62.0
Mixed	513	387	75.4	45	54.2
Asian or Asian British	677	543	80.2	88	72.7
Black or Black British	262	202	77.1	27	58.7
Other	353	245	69.4	52	54.2

Table 6 shows the religious group with the highest proportion of carers is Other (15.6%) followed by Jewish (10.9%) and Christian (10.8%). The religious group with the largest

^a Six ethnic groupings have been created based on the census categories. It is acknowledged that variation is found within these groups. Data for each group can be found on the ONS website.³

number of carers overall is Christian (12,710) followed by No religion (7,634). Carers identifying as Muslim are most likely to be providing more than 50 hours of care a week (24.8%) followed by those carers who are Jewish (24.0%).

Table 6: Provision of unpaid care in Brighton & Hove by religion and number of hours of care provided (Census 2011)

Religion	All persons	All persons providing unpaid care (% of religious group providing care)		Percentage of total carers in each religious group	Provides 1 to 19 hours unpaid care a week (% of religious group providing 1 to 19 hours care)		Provides 20 to 49 hours unpaid care a week		Provides 50 or more hours unpaid care a week	
		No.	%		No.	%	No.	%	No.	%
Christian	117,276	12,710	10.8	58.2	8,270	65.1	1,579	12.4	2,861	22.5
Buddhist	2,742	266	9.7	1.2	203	76.3	32	12.0	31	11.7
Hindu	1,792	126	7.0	0.6	84	66.7	23	18.3	19	15.1
Jewish	2,670	292	10.9	1.3	191	65.4	31	10.6	70	24.0
Muslim	6,095	427	7.0	2.0	236	55.3	85	19.9	106	24.8
Sikh	342	25	7.3	0.1	21	84.0	*	*	*	*
Other	2,409	375	15.6	1.7	283	75.5	37	9.9	55	14.7
No religion	115,954	7,634	6.6	34.9	5,611	73.5	837	11.0	1,186	15.5

Table 7 shows that carers identifying as Hindu (80.2%) and Sikh (80.0%) religious groups are most likely to say they are in good health, and carers identifying as Jewish (66.1%) and Other religion groups are least likely to report good health. When caring for more than 50 hours a week, this figure drops dramatically for most religious groups with the exception of carers from Buddhist and Muslim groups. Carers who identify as Hindu are least likely (43.5%) to report good health when caring more than 50 hours a week, followed by carers from Jewish groups (45.7%).

Table 7: Provision of unpaid care in Brighton & Hove by religious group and self-rated health status (Census 2011)

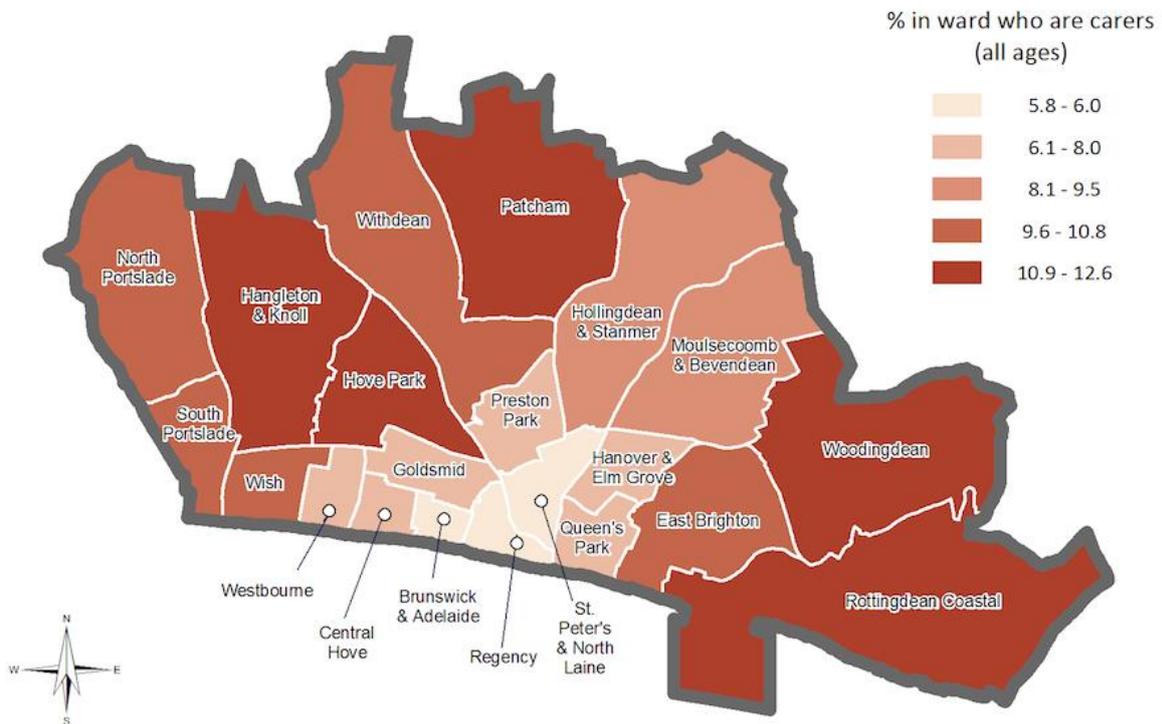
Religion	All persons providing unpaid care	Carers who are in 'very good or good health'		Provides 50+ hours unpaid care a week & in 'very good or good health'	
		No.	%	No./ providing 50+ hours	%
Christian	12,710	8,966	70.5	1,497/2,861	52.3
Buddhist	266	206	77.4	22/31	71.0
Hindu	126	101	80.2	10/23	43.5
Jewish	292	193	66.1	32/70	45.7
Muslim	427	321	75.2	75/106	70.8
Sikh	25	20	80.0	*	*
Other	375	250	66.7	29/55	47.3
No religion	7,634	5,978	78.3	761/1,186	64.2

The data on unpaid care is also available by ward (see Table 8 and Figure 1). This data shows a large variation in the number of carers and percentage of the population in caring roles in the wards in Brighton & Hove. The wards with the overall highest numbers of carers are Hangleton and Knoll, Patcham and Moulsecoomb and Bevendean. The percentage of the population in a caring role varied between 5.7%-11.8%, with the wards with the highest percentage of residents who are carers being Woodingdean, Patcham and Hangleton and Knoll.

Table 8: Provision of unpaid care in Brighton & Hove by ward (Census 2011)

Ward	Population	Number of carers	% of population in the Ward who are carers
Woodingdean	9,783	1,159	11.8
Patcham	14,195	1,666	11.7
Hangleton and Knoll	14,676	1,707	11.6
Rottingdean Coastal	13,171	1,494	11.3
Hove Park	10,460	1,160	11.1
South Portslade	9,421	960	10.2
Withdean	14,372	1,472	10.2
North Portslade	10,031	1,002	10.0
Hollingdean and Stanmer	12,869	1,271	9.9
East Brighton	13,956	1,372	9.8
Wish	9,548	934	9.8
Moulsecoomb and Bevendean	16,537	1,581	9.6
Queen's Park	14,667	1,155	7.9
Westbourne	9,585	748	7.8
Goldsmid	15,326	1,184	7.7
Central Hove	9,138	648	7.1
Hanover and Elm Grove	15,751	1,080	6.9
Preston Park	14,717	1,021	6.9
Regency	9,808	577	5.9
Brunswick and Adelaide	10,072	584	5.8
St. Peter's and North Laine	17,976	1,022	5.7

Figure 1: Provision of unpaid care in Brighton & Hove by ward (Census 2011)



Public Health Intelligence, Brighton and Hove
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The age profiles of the carers in the different wards varied:

- Moulsecoomb and Bevendean (16.1%), Hanover and Elm Grove (14.6%), and St Peter's and North Laine (14.8%) have the highest proportion of 0-24 year old carers.
- Brunswick and Adelaide (49%), Central Hove (46.8%) and Regency (46.8%) have the highest proportion of 25-49 year old carers.
- Hove Park (43.3%), Rottingdean Coastal (39.3%) and Withdean (39.1%) have the highest proportion of 50-64 year old carers.
- Rottingdean Coastal (27.9%), Withdean (24.0%) and Hove Park (23.3%) have the highest proportion of carers aged 65 and over.

Table 9: Provision of unpaid care in Brighton & Hove by ward and by age (Census 2011)

Ward	0-24 years (number, %)		25-49 years (number, %)		50-64 years (number, %)		65+ years (number, %)	
	number	%	number	%	number	%	number	%
Brunswick and Adelaide	40	6.8	286	49.0	186	31.8	72	12.3
Central Hove	31	4.8	303	46.8	179	27.6	135	20.8
East Brighton	154	11.2	639	46.6	383	27.9	196	14.3
Goldsmid	68	5.7	488	41.2	408	34.5	220	18.6
Hangleton and Knoll	160	9.4	603	35.3	570	33.4	374	21.9
Hanover and Elm Grove	158	14.6	472	43.7	326	30.2	124	11.5
Hollingdean and Stanmer	129	10.1	522	41.1	401	31.5	219	17.2
Hove Park	62	5.3	326	28.1	502	43.3	270	23.3
Moulsecoomb and Bevendean	255	16.1	681	43.1	390	24.7	255	16.1
North Portslade	100	10.0	385	38.4	327	32.6	190	19.0
Patcham	115	6.9	572	34.3	593	35.6	386	23.2
Preston Park	69	6.8	418	40.9	392	38.4	142	13.9
Queen's Park	94	8.1	464	40.2	387	33.5	210	18.2
Regency	54	9.4	270	46.8	176	30.5	77	13.3
Rottingdean Coastal	68	4.6	422	28.2	587	39.3	417	27.9
South Portslade	81	8.4	378	39.4	336	35.0	165	17.2
St. Peter's and North Laine	151	14.8	473	46.3	285	27.9	113	11.1
Westbourne	44	5.9	269	36.0	282	37.7	153	20.5
Wish	76	8.1	341	36.5	330	35.3	187	20.0
Withdean	70	4.8	473	32.1	576	39.1	353	24.0
Woodingdean	82	7.1	386	33.3	438	37.8	253	21.8

Figure 2: Provision of unpaid care in Brighton & Hove by ward and by proportion of those aged 0-24 years (Census 2011)

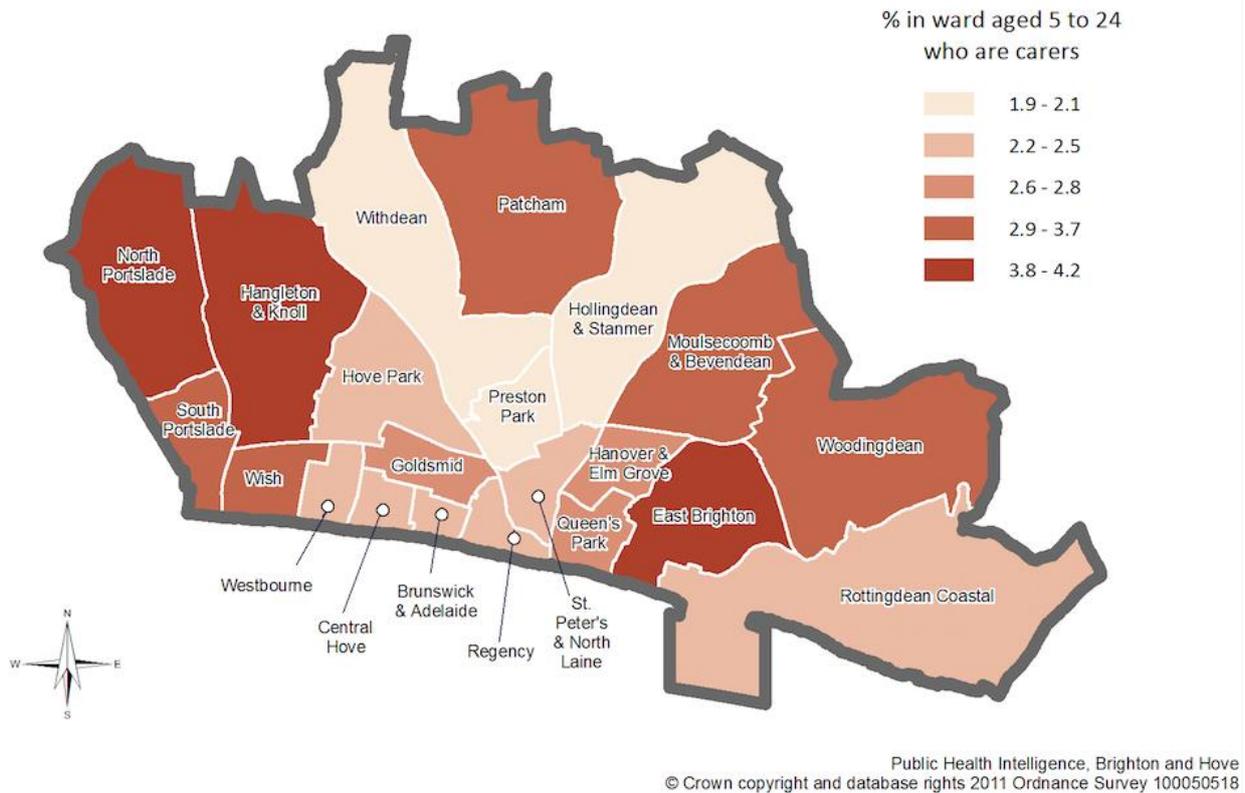
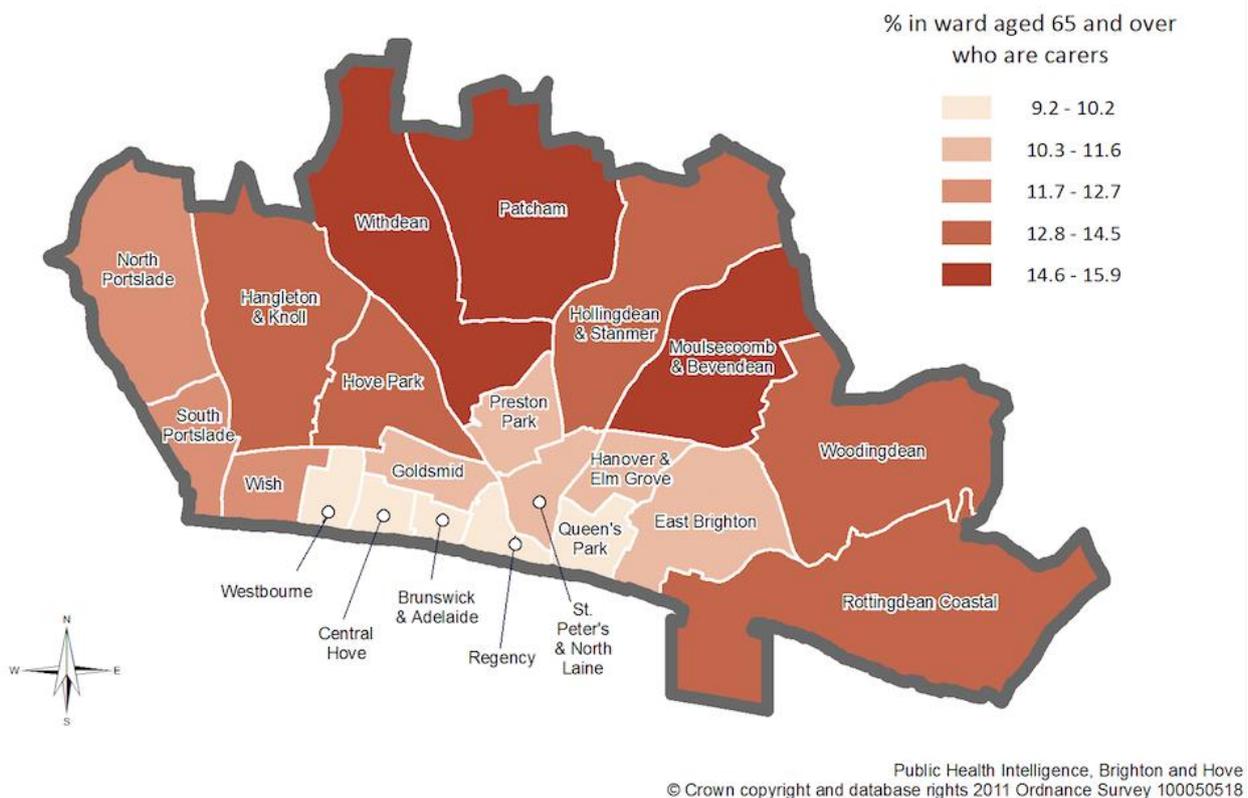


Figure 3: Provision of unpaid care in Brighton & Hove by ward and by proportion of those aged over 65 years (Census 2011)



The data by ward is also available by ethnicity, which is grouped into 5 categories for ease of analysis. The wards with the highest proportion of White British and White Other carers are Patcham (96.0%) and Woodingdean (95.9%) and Regency has the lowest proportion (89.0%). The wards with the highest proportion of Mixed carers are found in St Peter's and North Laine (3.8%). The highest proportion of Black or Black British carers is in Queen's Park (1.7%). Numbers smaller than 5 have been suppressed in the table to protect anonymity.

Table 10: Provision of unpaid care in Brighton & Hove by ward and by ethnicity (Census 2011)

Ward	White British & White Other		Mixed		Asian/Asian British		Black/Black British		Other	
	No.	%	No.	%	No.	%	No.	%	No.	%
Brunswick and Adelaide	531	90.5	17	2.9	24	4.1	6	1.0	9	1.5
Central Hove	595	91.7	20	3.1	12	1.8	9	1.4	13	2.0
East Brighton	1,262	91.8	31	2.3	34	2.5	19	1.4	28	2.0
Goldsmid	1,079	90.2	26	2.2	45	3.8	21	1.8	25	2.1
Hangleton and Knoll	1,560	91.4	29	1.7	57	3.3	23	1.3	38	2.2
Hanover and Elm Grove	1,007	92.4	27	2.5	32	2.9	12	1.1	12	1.1
Hollingdean and Stanmer	1,222	92.5	22	1.7	42	3.2	19	1.4	16	1.2
Hove Park	1,060	91.1	24	2.1	49	4.2	*	*	25	2.1
Moulsecoomb and Bevendean	1,464	91.4	47	2.9	44	2.7	23	1.4	23	1.4
North Portslade	951	94.9	11	1.1	23	2.3	11	1.1	6	0.6
Patcham	1,600	96.0	24	1.4	24	1.4	10	0.6	8	0.5
Preston Park	965	94.4	17	1.7	31	3.0	*	*	*	0.4
Queen's Park	1,052	89.5	31	2.6	48	4.1	20	1.7	25	2.1
Regency	519	89.0	21	3.6	28	4.8	*	*	10	1.7
Rottingdean Coastal	1418	94.5	22	1.5	31	2.1	8	0.5	22	1.5
South Portslade	910	93.9	18	1.9	10	1.0	15	1.5	16	1.7
St. Peter's and North Laine	927	89.5	39	3.8	38	3.7	17	1.6	15	1.4
Westbourne	695	92.1	16	2.1	24	3.2	12	1.6	8	1.1
Wish	850	90.7	32	3.4	20	2.1	11	1.2	24	2.6
Withdean	1,383	93.9	21	1.4	45	3.1	8	0.5	16	1.1
Woodingdean	1,112	95.9	18	1.6	16	1.4	*	*	10	0.9

* = numbers smaller than 5 are suppressed to protect anonymity

When considered overall, the proportion of carers from ethnic groups other than White British and White Other varied by ward with Regency (11.0%) having the highest proportion and Patcham (4.0%) having the lowest.

4.2 Projected increase in number of older carers

The number of older carers is also increasing at a rapid pace. Nationally the number of carers over 80 has risen to 417,000, an increase of 39% from 2009.⁴ In Brighton & Hove it is estimated that there were 5,052 people aged 65 and over providing unpaid care in 2015, and this is conservatively estimated to rise to 6,708 by 2030.⁵

4.3 Carers allowance

Carers allowance is the main benefit available for carers who are caring more than 35 hours a week, and data is available from the Department of Work and Pensions (DWP). The number of carers receiving carers allowance has increased significantly between 2005 and 2015 both in England overall and in Brighton & Hove. There were large increases in the under 35s for both men and women, although this was slightly larger for males.

Table 11: Carers allowance recipients in Brighton & Hove by gender in 2005 and 2015 (DWP)

Age	England		Brighton					
	May 2005	May 2015	May 2005			May 2015		
			TOTAL	Males	Females	TOTAL	Males	Females
Age 18 to 24	3,890	11,760	50	20	30	120	50	70
Age 25 to 34	9,140	22,820	240	50	190	430	100	330
Age 35 to 49	32,050	56,100	750	170	580	1,060	210	850
Age 50 to 64	43,590	77,550	480	180	300	810	330	480
Age 65+	1,720	2,670	30	10	20	70	10	60
TOTAL	90,390	170,900	1,560	430	1,130	2,640	710	1,930

5. Analysis of data from Adult Social Care

5.1 Carers in contact with the Carers Service

Brighton and Hove City Council, Adult Social Care, and the Brighton and Hove Clinical Commissioning Group have joint commissioning arrangements for the provision of dedicated support for carers. Funding a range of services, both within the statutory and voluntary sector, to ensure that the diverse needs of carers are supported, including awareness raising, information, advice and targeted specialist services. Additionally, the Supporting Carers Better Care Programme, which aims to ensure that the needs of carers are embedded across the Better Care agenda, providing dedicated funding to pilot a range of new support initiatives for carers, currently until March'17.

Jointly Commissioned Carers Services 2015/16

Alzheimer's Society - Information, Advice and Support for carers of people with dementia and training	Carers Centre -Adult Carers Support – information, advice, peer support, activities	Sussex Community Trust - Carers Back Care Advisor	Carers Centre - Young Carers Support – information, advice, peer support and group activities
Crossroads - My Health Matters – health related appointments - Better Care Pilot	Crossroads Homebased respite for Parent Carers	Carers Centre - Support for carers of people at the End of Life	Carers Centre - Carers Engagement
Early Help - Whole Family support worker	Pavilion - Information, Advice and Support for carers of people with substance misuse issues	Carers Emergency Back Up Scheme (Carelink Plus)	Carers Centre - Carers Reablement Project - Better Care Pilot
ASC Working Carers Project - Better Care Pilot	Integrated Primary Care Team Carer Support Workers	ASC Hospital Carer Support Workers - Better Care Pilot	ASC Carers Budget for breaks and services for carers (projects and personal budgets)

Collated data was available for the period of April - December 2015, 1123 carers accessed Brighton & Hove City Council's Carers Service (within Adult Social Care). The primary support reasons of carers noted by this service are listed below, with three quarters of carers seeking social support.

Table 12: Primary support reasons for carers accessing the Carers Service (ASC data)

Carers Primary Support Reason	No. of carers	% of carers
Social Support to carer	845	75.2
Physical Support Access & mobility only	96	8.5
Physical Support for Personal care	96	8.5
Learning Disability Support	40	3.6
Memory and Cognition Support	17	1.5
Social Support - social isolation / other	13	1.2
Mental Health Support	8	0.7
Sensory Support for hearing impairment	*	*
Sensory Support for visual impairment	*	*
Social Support - Substance misuse	*	*
Grand Total	1,123	

* = numbers smaller than 5 are suppressed

When comparing the gender split of carers for those accessing the Adult Social Care Service, and the carers overall in Brighton & Hove, those carers who contact the service are more likely to be female (65%) compared to the overall population of carers in Brighton & Hove (57.6%) as described by the Census 2011 data.

Table 13: Comparison of gender split for carers accessing the Carers Service and Census data (ASC data/Census 2011)

Gender	ASC Data		Census 2011 Data	
	Female	730	65%	13,703
Male	393	35%	10,094	42.5%
TOTAL	1,123		23,797	

Carers who contact the Carers Service are more likely to be over the age of 65, compared to the carers in Brighton & Hove overall and are less likely to be 'working age' carers (18-64 years).

Table 14: Comparison of age groups for those accessing the Carers Service and Census Data (ASC data/Census 2011)

Age Group	Brighton & Hove Carers (Census) %	Carers Service	
		No. of carers	%
Under 18	1.2 ^b	21	1.9
18-64 years	86.0	624	55.6
65+ years	12.8	478	42.6

Of the carers who accessed the Carers Service, the largest grouping (32.2%) said they were Christian, followed by no religion (17.1%). However this data is difficult to interpret as almost half of carers did not complete the question. Comparison to Census data is difficult due to the amount of missing data, but it appears that some religious groups may be under-represented in the Carers Service.

^b The Census data uses the age category 16-64 years.

Table 15: Comparison of religious groups for those accessing the Carers Service and Census Data (ASC data/Census 2011)

Religion	Brighton & Hove Carers (Census) %	No. of carers	% of carers
Christian	58.2	362	32.2
Buddhist	1.2	*	*
Hindu	0.6	*	*
Jewish	1.3	10	0.9
Muslim	2.0	9	0.8
Sikh	0.1	*	*
Other	1.7	25	2.2
None	34.9	192	17.1
Unknown	-	519	46.2

* = numbers smaller than 5 are suppressed to protect anonymity

Almost 2% of carers accessing the Carers Service described themselves as lesbian or gay, with 55.6% saying they were heterosexual. This was another question with large amounts of data missing, making interpretation of the data difficult.

Table 16: Self-reported sexuality of carers accessing the Carers Service (ASC data)

Sexuality	No. of carers	%
Heterosexual	624	55.6
Lesbian/Gay	21	1.9
Other	*	*
Info not available	477	42.5

* = numbers smaller than 5 are suppressed to protect anonymity

5.2 Carers' assessments

Carers have had the right to a carer's assessment for several years, however in order to access them the carer had to approach the local authority and prove they were providing regular and substantial care. The Care and Support Act (2014) enforces local authorities to be more proactive in supporting carers, from identification to assessment, and if a carer feels they are being affected by their caring role, then the local authority has a legal duty to provide an assessment.

A carer's assessment considers the impact the care and support the carer is providing is having on their own wellbeing, as well as other important aspects of the carer's life such as education or employment. The carer will then receive information on the services they are eligible for and appropriate support and information.

Between 1st April 2015 and 31st December 2015, 359 carer's assessments were completed. These are completed on carers over the age of 18 who are caring for an adult.

5.2.1 Demographics

The carers having a carer's assessment had a similar age distribution to those accessing the Carers Service, which reflects an older age profile than the carers identified in the census. For example, in the census 86.0% of carers were of working age, compared to 56.7% of those receiving a carer's assessment.

Table 17: Comparison of age groupings of carers accessing Carer’s Assessment, the Carers Service and Census (ASC data/Census 2011)

Age Group	Brighton & Hove Carers (Census) % ^c	Carers Assessment (ASC) %	Carers Service (ASC) %
18-64 years	86.0	56.7	55.6
65+ years	12.8	42.3	42.6

Further information was available on age groups for those accessing the carer’s assessment and this is presented below. The largest age group represented is the 55-64 year olds (25.1%), followed by the 65-74 year olds (22.0%). It is worth noting that 20.3% of the carers are between 74-94 years old which represents a large proportion compared to the census figures and could be indicative of a particularly vulnerable population.

Table 18: Age groupings of carers accessing Carers Assessment (ASC data)

Age Group	No. of carers	%
18-24	6	1.7
25-34	6	1.7
35-44	29	8.1
45-54	72	20.1
55-64	90	25.1
65-74	79	22.0
75-84	52	14.5
85-94	21	5.8
95+	*	-
TOTAL	359	

Information about carers from the Carers’ Assessments

- 97.8% of carers stated that their preferred language was English.
- 3.3% of carers stated that they were either deaf or blind.
- 2.8% of carers said that they had ‘communication difficulties’ (no further information available).
- 32.9% of carers shared their caring role with another family member or friend, and 6.8% of these family members or friends were under 18.

Of those having a carer’s assessment, 79.4% of carers lived with the person that they cared for. Most were caring for a family member (78.6%), with smaller numbers caring for a spouse/partner (15.0%).

Table 19: Relationship between the carer and the person they are caring for (ASC data)

Who the person is caring for	No. of carers	% of carers
Family member	282	78.6
Spouse/partner	54	15.0
Friend	8	2.2
Other	8	2.2

^c The Census data uses the age category 16-64 years.

5.2.2 Impact of caring

In this section of the assessment, carers are asked about how their caring role affects different areas of their life, and the impact that this has on their wellbeing. Carers are asked yes/no questions about different areas and then asked to rate the impact on their wellbeing from 'no impact' to 'major impact'.

All results are presented as a percentage of the total carers' assessments, due to inconsistencies in the data that prevent further analysis. For example, 55 carers said they had a dependent child but 83 carers answered the question about whether caring impacts on their parenting duties (Y/N) and 100 carers rated the impact on their wellbeing (no impact/significant impact/major impact). The percentages will not add up to 100% as there are missing data for each question.

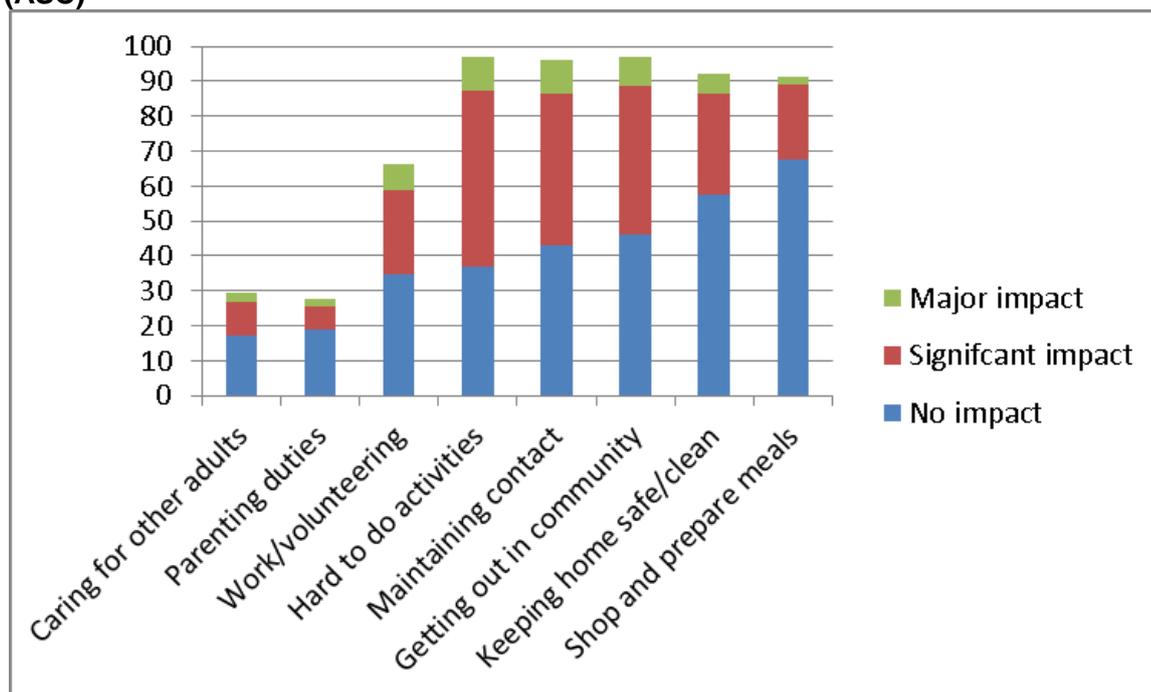
The areas that the highest proportion of carers said their caring role affected were 'undertaking leisure, cultural or spiritual activities' (65.5%), 'maintaining contact with people important to you' (60.4%) and 'getting out into the community' (56.7%). A high proportion of carers said that these three areas had a major impact on their wellbeing.

Table 20: Areas of life impacted by caring, and rated severity of impact (ASC data)

Area impacted by caring (question in assessment)	Carers who answered YES (%)	No impact (%)	Significant impact (%)	Major impact (%)
Does your caring role make it difficult to keep your home sufficiently clean and safe?	141 (39.3%)	207 (57.7%)	103 (28.7%)	27 (5.8%)
Does your caring role make it difficult to shop for and prepare adequate meals for yourself?	107 (29.8%)	243 (67.7%)	77 (21.4%)	8 (2.3%)
Do you have any children that are dependent on you?	55 (15.3%)			
If 'Yes', does your caring role impact on carrying out your parenting duties?	35 (9.7%)	68 (18.9%)	23 (6.4%)	9 (2.5%)
Do you have caring responsibilities for other adults?	58 (16.2%)			
If 'Yes', does your caring role make it more difficult to meet these responsibilities?	41 (11.4%)	61 (17.0%)	36 (10.0%)	9 (2.5%)
Does your caring role make it difficult to maintain contact with people important to you?	217 (60.4%)	155 (43.2%)	155 (43.2%)	35 (9.7%)
Does your caring role make it difficult for you to get out into the community?	207 (56.7%)	166 (46.2%)	152 (42.3%)	30 (8.4%)
Does your caring role make it difficult to undertake leisure, cultural or spiritual activities?	235 (65.5%)	133 (37.0%)	181 (50.4%)	34 (9.5%)
Does your caring role impact on your involvement in work/training/education/volunteering?	140 (40.0%)	124 (34.5%)	87 (24.2%)	27 (7.5%)

Figure 5 shows each area and the impact that is reported by carers, with percentages for each impact of total carers assessments.

Figure 5: Areas of life that are affected by caring, and the rating of their impact on wellbeing (ASC)



5.2.3 Employment and education

When asked about their working status, the highest proportion of carers were retired (41.8%) which reflects the age spread of the carers having a carer’s assessment with Adult Social Care. About a quarter (23.9%) of carers were employed, with another quarter unemployed and not seeking work (24.8%). As seen in Table 20, 40.0% of carers said that their caring responsibilities impacted on their involvement in work and education, and 31.7% said this was having a ‘significant’ or ‘major’ impact on their wellbeing.

Table 21: Work status of carers having a Carers Assessment (ASC data)

Work Status	No. of carers	% of carers
Employed 16 hours +	66	18.4
Employed 5-16 hours	12	3.3
Employed <4 hours	8	2.2
Voluntary Work	11	3.1
Not working (seeking work)	23	6.4
Not working (not seeking work)	89	24.8
Retired	150	41.8

Related to this, 36.5% of carers said that they were experiencing financial difficulties. 46.2% of carers said they or the person they care for had had a benefits check.

5.2.4 Health

75.5% of carers said that their GP was aware that they were a carer; for those that said their GP wasn’t aware, 56.5% (39/69) said they would be happy for their GP to be contacted.

In the carer’s assessment, carers are asked about the risk of their mental and physical health deteriorating due to their caring role. Most carers (91.4%) felt there was some risk of their mental health deteriorating, with over half (52.1%) rating themselves as being at ‘significant’ or ‘serious’ risk. These figures were similar for physical health, with 86.9%

feeling that they were at some risk and 37.6% rating themselves as being at ‘significant’ or ‘serious’ risk. It could be suggested that the assessed risk to physical health is lower because of less understanding about these risks- but this would need to be investigated with carers themselves.

Table 22: Impact of caring on the risk to mental and physical health rated by carers having a Carers Assessment (ASC data)

Impact of caring	No risk (%)	Low risk (%)	Significant risk (%)	Serious risk (%)
What is the risk of your mental health deteriorating due to your caring role?	26 (7.24%)	141 (39.3%)	139 (38.7%)	48 (13.4%)
What is the risk of your physical health deteriorating due to your caring role?	43 (12.0%)	177 (49.3%)	118 (32.9%)	17 (4.7%)

Three questions in the assessment focus on the carer’s ability and willingness to continue caring and their concerns about the future. Almost half of the carers undertaking the assessment said they did not feel able to continue with their caring role (47.9%) or felt willing to continue (46%). This is indicating a high level of difficulty associated with the caring role and potentially high levels of mental distress. Over three quarters of carers (76.3%) said they had concerns about the longer term future. When asked ‘Have you ever felt distressed or in danger due to the behaviour of the person you care for?’, 18.1% of the carers answered Yes.

Table 23: Ability/willingness to continue caring and concerns about the future by carers having a Carers Assessment (ASC data)

Question	No. of carers who answered YES	% of carers who answered YES
Are you able to continue with your caring role?	187	52.1
Are you willing to continue with your caring role?	194	54.0
Do you have concerns about the longer term future?	274	76.3

5.3 Caring for Others Survey 2014-15⁶

This is an annual survey sent out by post to a random selection of carers over 18 in contact with Adult Social Care. The aim is to seek the views and opinions of carers in the city to find out whether or not services received are helping them in their caring role and their life outside caring, and also their experience of services provided to the cared for person.

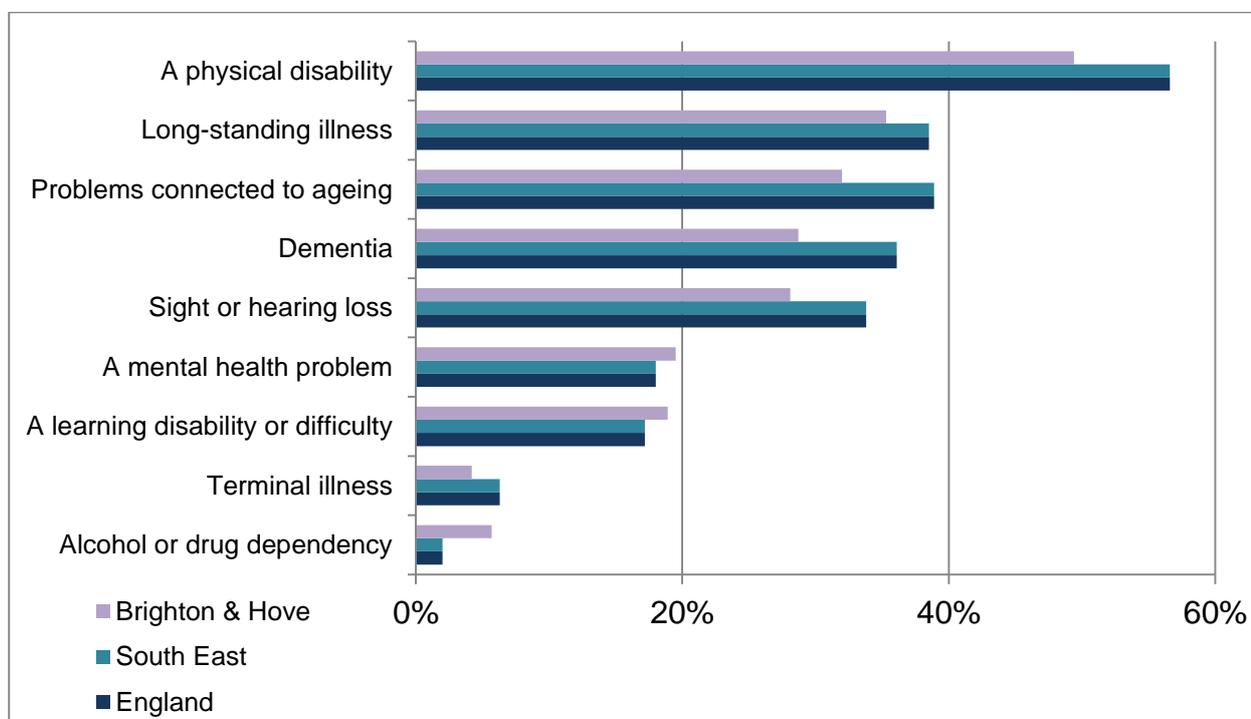
In 2014-15, the survey was sent to 766 carers in Brighton & Hove and 43.3% (332) were returned. Follow up phone calls were made with 55 respondents to seek additional information on their comments. The demographics of the respondents were noted as being

largely similar to the carers seeking support from Adult Social Care. 64.9% of carers had a health condition themselves.

The primary support reason of the cared for person was predominantly either physical health (39.4%) or a learning disability (37.9%), with the next largest group caring for those with a mental health problem (10.8%). When asked about the health condition that the person they care for has, a range of answers were given which are details in Figure 6. In many cases these will be multiple.

This survey is carried out nationally by councils with adult social services responsibilities, and as can be seen in Figure 6 there is variation between Brighton & Hove, the South East, and England. In particular 6% of local carers are providing care for somebody with an alcohol or drug dependency, compared to 2% regionally and nationally.

Figure 6: Health conditions of the person carers are caring for (Survey of Adult Carers 2014-15)^d



Of those receiving services, 60.7% said they were satisfied with the support they had received over the last 12 months- this is compared to 58.2% in the 2012 -13 survey. 8.4% reported that they were dissatisfied with services, compared to 9.5% in 2012 -13.

5.3.1 Needs and experiences of support

When asked about the services that they accessed over the last 12 months, the most common listed were ‘information and advice’ (52%), the Carers Card (39%) and ‘support from carers groups’ (28%). These services may have been provided by other organisations in addition to Adult Social Care.

^d Data source: Personal Social Services Survey of Adult Carers in England, 2014-15
<http://www.hscic.gov.uk/catalogue/PUB18423>

5.3.2 The impact of caring

When asked about how they spend their time, 25.5% of carers agreed 'I am able to spend my time as I want, doing things I enjoy or value' and 10.8% said 'I don't do anything I value or enjoy with my time'. A similar proportion (10.3%) said 'I have no control over my daily life'.

When asked about how much time they have to look after themselves (e.g. getting enough sleep or eating well), 28.9% of carers said that they didn't look after themselves well enough and 13.1% felt they were neglecting themselves. 14% of carers said they were concerned about their personal safety.

Social isolation was a big issue for carers with 43.7% saying they did not have enough social contact and 13.5% said they felt socially isolated. Additionally, 38.6% of carers felt they did not get enough support and encouragement in their role as a carer, and 16.8% felt they had no encouragement and support.

Although the proportion of people reporting negative experiences is low, and less than the previous year in most cases, these figures are of concern as 80% of the carers responding to the survey have been in contact with Adult Social Care in the last 12 months.

5.3.3 Information and advice

21.7% of carers felt it was fairly or very difficult to find information or advice about support, services or benefits in the last 12 months. 68.5% of carers had received helpful information and advice, and 5.4% felt it had been unhelpful.

The report identifies three themes for action (information & advice, active & supportive communities, flexible and integrated care and support) and details plans in place for addresses these issues.

6. Feedback from local providers: Expert Panel

An Expert Panel^e was convened to gain the views and insight of local stakeholders. It was agreed that this was an appropriate method as the needs assessment was conducted in a short timescale. The Expert Panel was conducted through a meeting of the Carers Strategy Group hosted by the local authority and chaired by a carer. This group is made up of representatives from Adult Social Care and third sector organisations working with carers. During this panel, representatives were asked for their feedback on the following areas:

- Existing data they collect on carers
- Service mapping
- Local needs/ Barriers to access
- Information on users and potential users of services
- Strengths, gaps and duplications in services

^e This method was adapted from the method described in the following document: NHS. (2007). Sexual Health Needs Assessments: A how to guide. Available online: www.apho.org.uk/resource/view.aspx?RID=74982 Accessed 13 Apr 2016.

A list of reports provided by the different organisations that attended is in Appendix A. These reports are held by the Carers Commissioner at the local authority in order to inform commissioning decisions in the future.

Representatives were asked to outline the services they provide using post-its on a map of the city. A summary of the service mapping carried out is in Appendix B.

Through discussions at the Panel a number of groups were identified that the attendees felt were either at high risk of poor outcomes, they didn't know enough about to provide adequate services or that services were just not in place (often a combination of these reasons). These groups are outlined in Section 8, with a summary of the information available about them.

Other issues raised included:

- Impact on social/physical/mental health for parent carers
- Gaps in access to other services for parent carers
- Gaps in services for bereaved carers
- Gaps in services for carers who looks after someone who is now resident in hospital or a care/nursing home
- How to engage with people who don't identify as carers
- Potential to identify/support carers through Job Centre Plus
- Access to reablement
- Understanding why people don't seek support before they reach crisis point
- Concerns about carers not fitting different 'eligibility criteria'

Strengths identified were:

- Joint working across agencies
- Range of resources and services available to carers

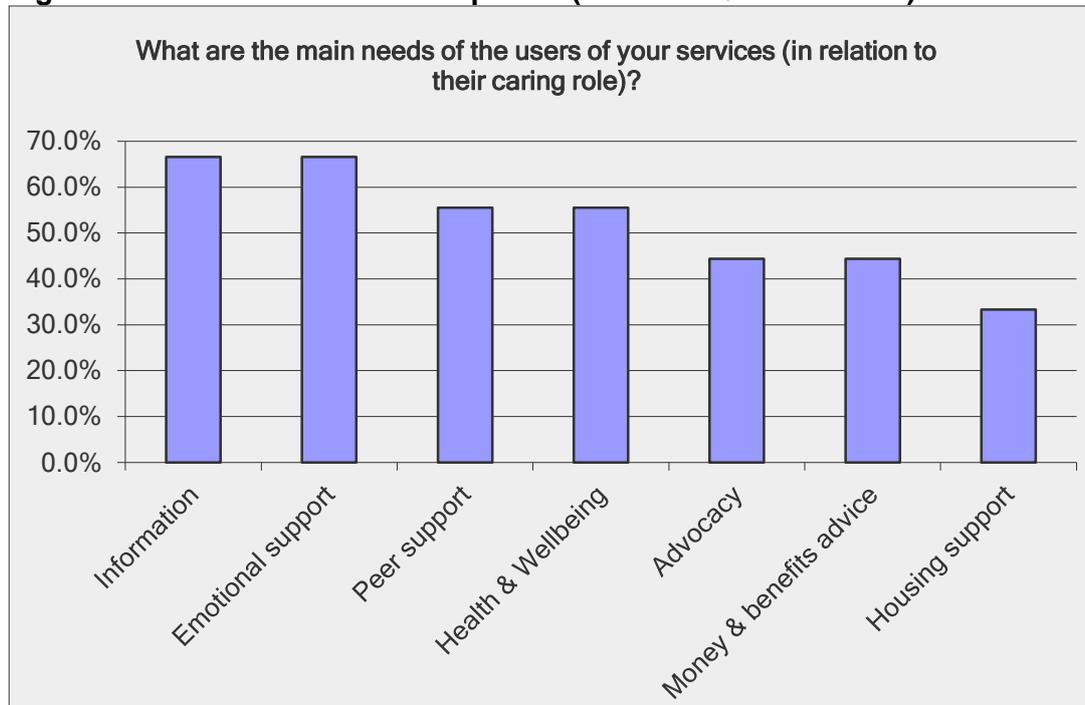
7. Feedback from local providers: Questionnaire

An online questionnaire was designed and promoted to voluntary sector organisations who provide services for carers, and additionally to those who provide services to those with mental health problems as this was felt to be an area of need by the Expert Panel. The link was sent out by Community Works, an organisation that connects the voluntary sector and holds email lists of organisations. The aim of the questionnaire was to gain views from the wider voluntary sector.

Nine organisations responded to the questionnaire, including those with clients with mental health problems, learning disabilities, children with disabilities and young carers. When asked if they mainly work with carers, 3 organisations said they did and 6 did not. 66.7% (6/9) of the organisations collected information on the 'protected characteristics' for people who accessed their services.

Figure 7 shows the responses about the main needs of carers that access the organisations' services. The highest proportion of organisations chose 'information', 'emotional support', 'peer support' and 'health and wellbeing' from the list of options provided.

Figure 7: Main needs of carers reported (Provider Questionnaire)



Strengths in provision for carers in Brighton & Hove were seen as:

- Amaze (organisation for parents of disabled children and children with special needs)
- The Carers Centre
- A high awareness of carers
- Tailored services for carers of people with dementia.

When asked about unmet needs, respondents mentioned:

- Services for working carers
- Advocacy for carers of people with long term health conditions (other than cancer)
- Prompt and clear signposting to services
- Respite and practical help
- Financial needs
- More support for parents of children with additional needs.

When asked about groups of carers that may be at additional risk or have additional needs that they need to know about in order to provide appropriate services, the groups mentioned were:

- older carers, carers for whom English is not their first language, disabled carers, Gypsy/Traveller carers, working carers (by 4 organisations)
- parents carers, BME carers, LGBT carers (by 3 organisations)

Other groups mentioned by fewer than three respondents were young carers, carers from particular faith backgrounds, carers who are unemployed, working age carers, single parent carers, long distance carers and carers with mental health issues.

When asked how organisations in the city could best engage with these identified groups, the following suggestions were made:

- reach out to them through the groups they already attend
- use GPs/pharmacies to identify them
- via local community groups and co-hosting workshops
- work with voluntary sector organisations that already work with these groups
- encourage peer support
- asking them what they would really find helpful.

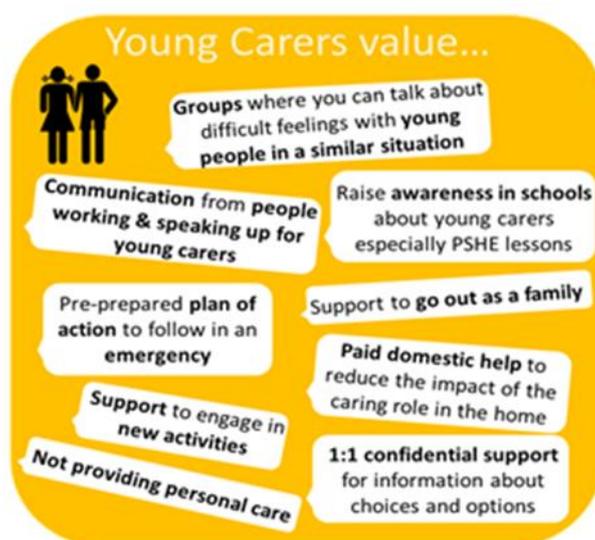
8. Needs of different groups of carers

The groups below were identified through the stakeholder feedback, and represent groups that are perceived to have higher needs, be at higher risk or just be a group that services feel more information is needed about.

8.1 Young carers

The number of identified young carers has been described in a national report as the ‘tip of the iceberg’, as many young carers remain hidden due to a range of reasons, including family loyalty, stigma, bullying, and not knowing where to go for support.⁷

The number of young carers aged 0-15 reported within the Census has increased from 11,964 in 2001 to 17,692 in 2011. This relates to an increase from 0.76% of all 0-15 year olds reported as carers to 1.06%. It is estimated that in England young carers are 1.5 times more likely to be from Black, Asian or minority ethnic communities.⁷ Additionally research has identified that the average annual income for families with a young carer is £5,000 less than families who do not have a young carer.⁷



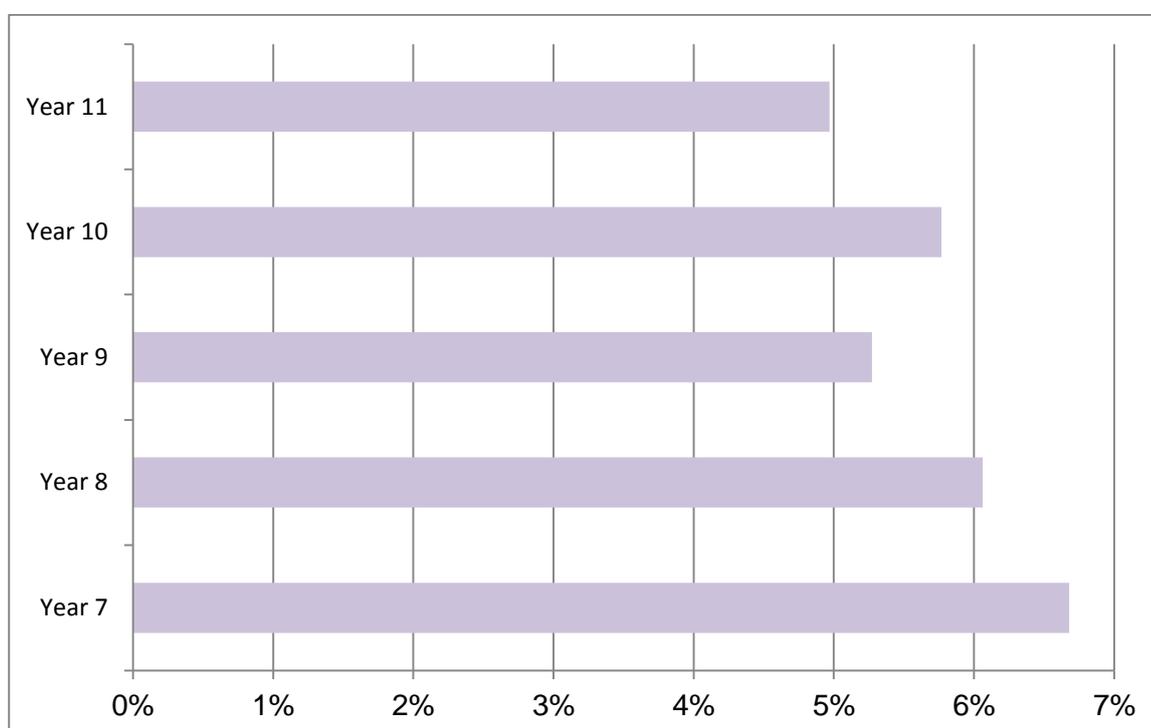
8.1.1 Safe and Well at Schools Survey

The Brighton & Hove Safe and Well at School Survey (SAWSS) is an anonymous online survey conducted annually by primary and secondary school pupils during lesson time. These results are taken from the seventh survey conducted in 2015. Each question on the survey has been analysed according to whether the young person identified as a carer or not, with the results being compared to those who do not identify as a young carer.

8.1.2 Demographics

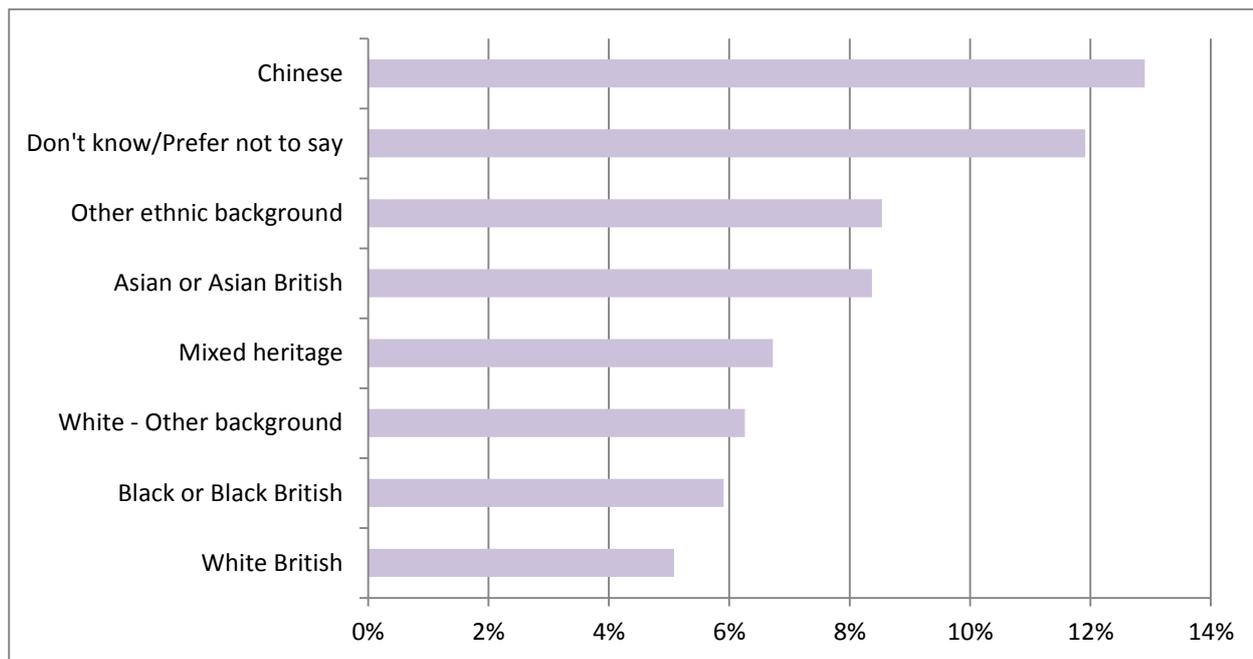
6% (526/9056) of young people aged 11-16 in secondary schools in Brighton identified as a 'young carer'. Of the young carers, 50% said they were a boy, 47% said they were a girl and 3% used 'another word' to describe their gender. This was a similar gender split to young people overall. Around half of the young carers are between 11-13 years old.

Figure 8: Percentage of each year group who are young carers (SAWSS 2015)



As shown in Figure 9, the ethnic group with the highest rate of young carers was Chinese with 13% of students identifying as a young carer. The ethnic group with the lowest rate was White British, with 5% young carers.

Figure 9: Percentage of each ethnic group who are young carers (SAWSS 2015)



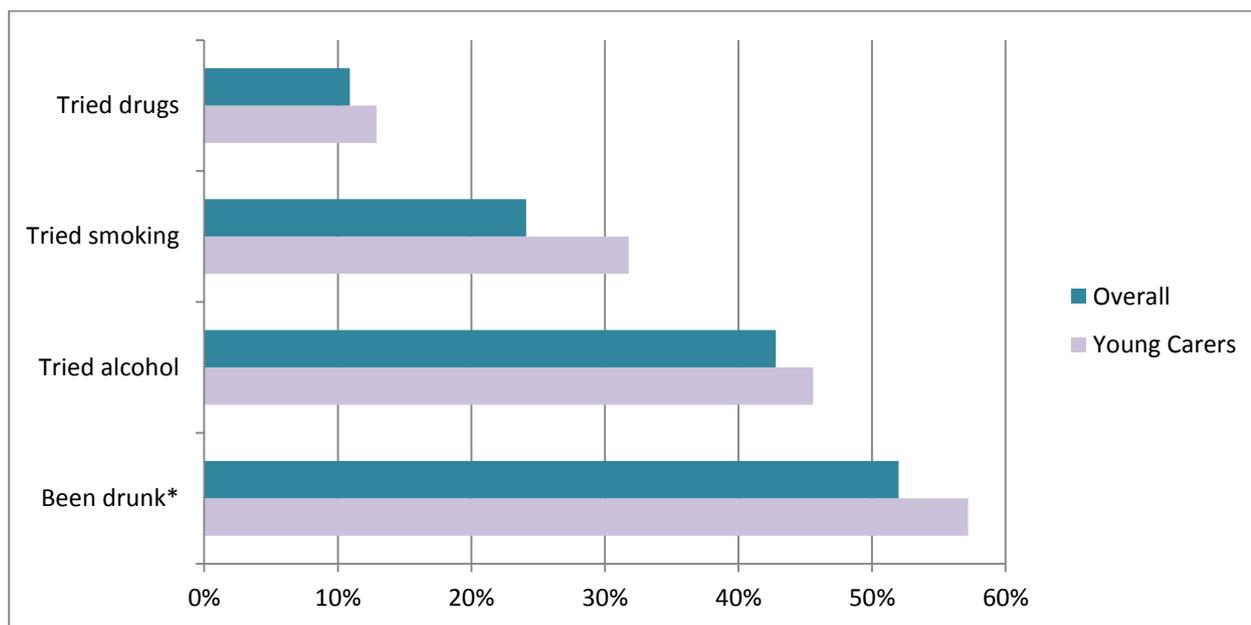
83% of young carers reported being heterosexual compared to 89% of non-carers- young carers were more likely to report being gay (7% of young carers vs. 5%) and unsure about their sexuality or prefer not to say (11% of young carers vs. 6%).

Young carers are less likely to live with both their mum and dad (48% of young carers vs. 63%), and more likely to live with mainly or only mum (28% young carers vs. 17%). Young carers are also more likely to be adopted (4% of young carers vs. 1%).

8.1.3 Health & wellbeing

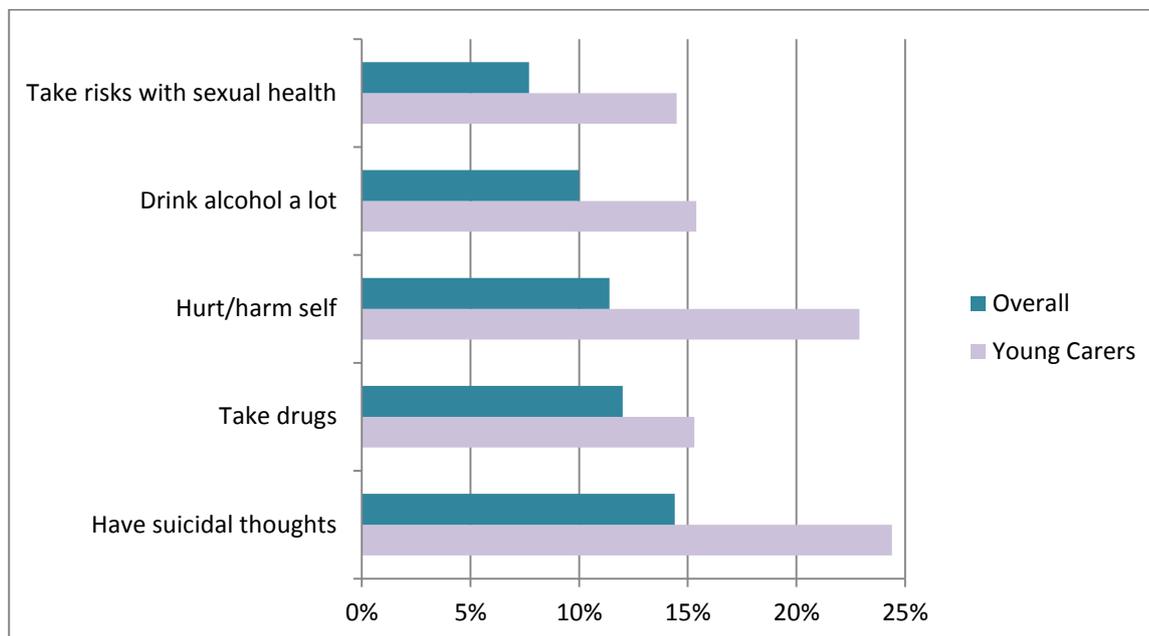
Young carers were more likely to put their health at risk in many ways, and to have experienced negative health and wellbeing. Figures 10 and 11 show that young carers are more likely to have experienced all the behaviours listed.

Figure 10: Percentage of young carers who have often or sometimes experienced risk taking behaviours, compared to young people overall (SAWSS 2015)



*The question 'Have you ever been drunk?' is limited to those students who previously answered that they had tried an alcoholic drink.

Figure 11: Percentage of young carers aged 14-16 who have often or sometimes experienced these behaviours, compared to young people overall (SAWSS 2015)

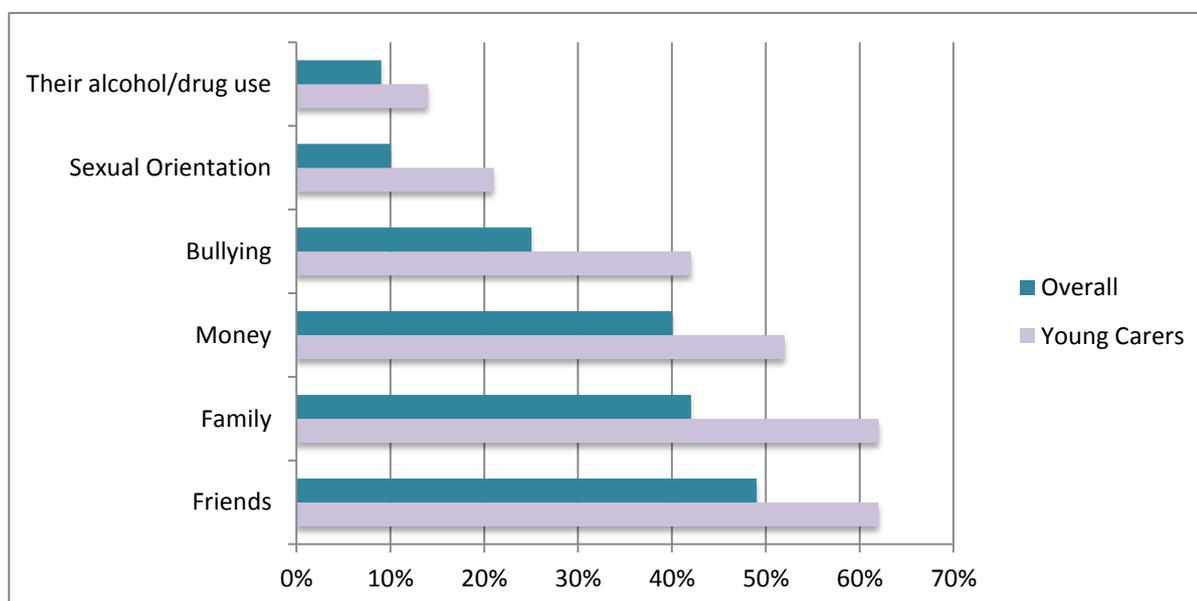


Young carers were more likely to have a regular smoker in the home (34% young carers vs. 18%) and to have been given cigarettes by a family member (7% young carers vs. 4%). Young carers are not significantly more likely to have reported trying alcohol, but out of those who have they are more likely to have ever been drunk (57% young carers vs. 52%). They are also more likely to have been given alcohol by a family member (23% of young carers vs. 19%).

For young people aged 14-16, young carers are more likely to have had sex (30% young carers vs. 19%), more likely to have been under 16 (30% young carers vs. 18%). Young carers are also more likely to have been touched sexually when they did not want it at school (22% of young carers vs. 14%) and more likely to have experienced ‘problem behaviours’ in a relationship (31% of young carers vs. 20%) such as being yelled at or put down and humiliated.

Young carers are also more likely to have problems relating to their mental wellbeing. Young carers are more likely to worry about problems with all the areas listed in Figure 12. They are less likely to feel happy with their life (72% of young carers vs. 83%) and more likely to have felt extremely miserable, angry and afraid in the last few weeks.

Figure 12: Percentage of young carers who worry about these problems, compared to young people overall (SAWSS 2015)



8.1.4 Bullying

Young carers were more likely to say that they had been bullied this term (28% of young carers vs. 13%) and less likely to say that the bullying had now stopped (15% of young carers vs. 21%). They are less likely to agree that they have someone to tell if they are being bullied (78% of young carers vs. 84%). Young carers were twice as likely to say that they had ever bullied someone at school (14% of young carers vs. 7%).

8.1.5 Education

Young carers are also more likely to be experiencing negative experiences related to their education. They were more likely to say that they didn’t enjoy coming to school (35% of young carers vs. 25%) and didn’t enjoy learning (30% of young carers vs. 21%). Young carers were also more likely to say that they didn’t feel safe at school (24% of young carers vs. 12%).

Young carers were more likely to have deliberately missed lessons at school (36% of young carers vs. 19%) and were more likely to have been excluded from school (15% of young carers vs. 8%).

8.1.6 Aspirations

When thinking about their future, young carers were less likely to say that they wanted to go to university (57% of young carers vs. 65%) and less likely to feel that they have enough information and support to plan their future (39% of young carers vs. 46%).

8.2 Parent carers

Parent carers are people with parental responsibilities (parents, grandparents, foster parents, adoptee parents and others) who also provide additional care, assistance and support to children with learning or physical disabilities, complex health needs or illness, or emotional behavioural difficulties. Parent carers face issues which are reflected by all carers; however there are further issues which are more specific to the needs of parent carers – including issues related to accessing educational support for the child they care for. Additionally, on average, it costs three times the amount to raise a disabled child compared to raising a child with no disabilities (5).

Amaze is a charity in Brighton & Hove that gives information, advice and support to parents and carers of children and young people with special educational needs and disabilities (SEND) and support to young people with SEND up to aged 25. Between April-December 2015, 305 questionnaires were completed by parent carers and the analysis highlighted the following information about parent carers.

Information about parent carers from the Amaze questionnaire

- 69% of parents carers spend 20 hours or more additional hours of caring a week because of their child's SEND, and 24% said it is an additional 100 hours a week.
- 44% of parent carers haven't had a break from their caring role in the past year
- 78% of parent carers said that they had not had their needs as a carer assessed
- 49% of parents carers reported that they don't have enough social contact, and 17% reported little or no social contact leading to isolation
- 31% reported that their caring role had stopped them being able to work
- 17% of parent carers reported having skipped meals or reduced portion sizes, as there wasn't enough money to feed the family.

8.3 'Older older' carers

Although this age group was not clearly defined, carers in higher age groupings were considered a group with additional risk and vulnerabilities. The Carers' Assessment data included responses from 73 carers over 75 years old, and these carers made up approximately 20% of the carers who had received an assessment. As most data sources group those over 65 years into one category, this could mean that information showing the diversity of older carers is lost.

8.4 Refugees

No information is currently available about refugees who may be carers in Brighton & Hove. Given this is a group who may not be easy to find out information about, and may find it difficult to access services, it is suggested that specialist workers with the local

authority and specialist organisations are approached to gain more information on this group and assess their needs as carers.

8.5 Carers of people with drug and alcohol problems

The only information in this report relating to caring for those with an alcohol or drug dependency is in the Caring for Others Survey, where 2.6% of carers said that they were caring for someone with these issues. Further information on this group of carers could be gained through working with drug and alcohol services in the city.

8.6 Carers of people with mental health problems

The only information in this report relating to caring for those with mental health problems is in the Caring for Others Survey, where 8.8% of carers said that they were caring for someone with these issues. Further information on this group of carers could be gained through working with mental health services within the city.

8.7 Armed Forces Carers

The Armed Forces Covenant (2011) outlines that the armed forces community should not face disadvantage because of their military service. This can mean giving special consideration to this group when providing health and care services.

The Carers Centre for Brighton & Hove is working with the Sussex Armed Forces Network on an initiative that aims to better support family carers from the Sussex armed forces and ex-armed forces community. A recent article written by the Carers Centre suggests that little is known about the needs of carers in the armed forces community, although there may be double the rate of carers (23%) compared to the general population. After adding an equalities monitoring question for armed forces personnel, the Carers Centre estimate that 5.6% of the carers they have seen have been from an armed forces background.

No information was available from Adult Social Care on the number of armed forces personnel in contact with their services.

8.8 Working age carers

Over three million carers in the UK combine work with caring responsibilities, including over two million who are working full-time. The State of Caring 2015 report by Carers UK⁸ notes that it can often be really difficult to juggle these responsibilities and a lack of support can lead to anxiety, stress and isolation. Many working carers say they go months without a break, with over two thirds of carers (68%) having used their annual leave to care and 46% having done overtime to make up hours spent caring.

Based on the census data there are nearly 19,000 working age carers (18-64 years) in Brighton & Hove, which represents around 86% of carers. This age group appears to be less likely to be in contact with Adult Social Care, and to have had a Carer's Assessment (only approximately 56% of carers in contact with these services are of working age).

Further work needs to be carried out in order to assess whether this age group's needs are being met.

8.9 Those who don't identify as carers

A major concern of stakeholders was identifying carers promptly and getting them the help and support they need. If a person does not identify as a carer, they will not appear in any of the statistics in this report and would not presumably therefore think to access services. It was suggested that carers could be asked about why they sought help when they did to help understand this situation, especially for those who only sought help when they reached crisis point. There is no specific information available about this group of carers at this time.

8.10 Caring for those in a home or hospital

This is a group it is felt may miss out on services because they are no longer caring for someone within their own home, as the person they care for has gone into hospital or into a care facility. There is no specific information about this group of carers available at this time.

8.11 Remote/distance carers

Another group of carers who were felt to be at higher risk of not receiving services were those caring for someone who was not living in the same local authority area, with either the carer or the cared for person living in Brighton & Hove. There is no specific information available about this group of carers at this time.

8.12 Key periods of transition

It was highlighted that carers may experience particular difficulties in times of transition, for example when the person they care for reaches 18 years old and the services they use or are entitled to change. There is no specific information available about this group of carers at this time.

8.13 Bereaved carers

Carers who have been bereaved were considered to be a group at higher risk. The Carers Centre in Brighton runs activities for carers who have been bereaved in the last year, and there is a support group who developed from this. There is no specific information available about this group of carers at this time.

9. Recommendations

1. Services and commissioners should consider how to target services at groups identified as being under-represented within services (e.g. males, working age carers).
2. Ensure that organisations that work with young people and with young carers specifically are aware that young carers are at increased risk of a number of poor outcomes and can respond to these risks including linking them into appropriate services such as physical and mental health services.
3. Ensure that impact of carers' services can be demonstrated by including the same questions in carer's reviews as the carer's assessment (for example, questions about the impact of caring on wellbeing and the risks to physical and mental health).
4. Ensure that the data collected by Adult Social Care is complete and quality checked, to provide a robust source of evidence about carers and their needs.
5. Ensure that Adult Social Care are collecting data on the protected characteristics for all carers accessing services, including religion and sexual orientation, as well as armed forces personnel.
6. Review the list of groups of carers at higher risk/with higher needs and prioritise those that more information is needed about or more specialised work is needed on. Research could be carried out with these groups to find out why they don't access services.

10. Appendix A: List of documents provided to Commissioner for Carers

Name of document	Date	Comments
1. Council Caring for Others Survey	2014/15	Demographics, info about the person they care for, services used, impact of caring- broken down into key themes
2. Carers Centre- feedback on hospital discharge process	2014	Feedback from 42 carers on discharge from hospital
3. Carers Centre- Activity Sheet	Oct 2015	Details of carers services across the city
4. Article for Veterans World	2014	Article with details of work with armed forces carers
5. Carers Centre- 6 month contract review	April- Sept 2015	Areas of activity, number accessing, some outcomes, evaluation reports of specific projects
6. Carers Centre- Adult KPIs	April- Sept 2015	Performance indicators and age breakdown of adult carers
7. Carers Centre- Young Carers KPIs	April- Sept 2015	Performance indicators and ethnicity of young carers
8. East Brighton Support Work KPIs	April- Sept 2015	Performance indicators
9. Carers Centre- Schools Work Report	2014-2015	Descriptive account of work in schools
10. Carers Star	April 2014	Outcomes of work with 16-25s on the carers star, and explanations of the star
11. Carers Centre- Activities and Groups	2015	Not included
12. AMAZE Parent Carers Questionnaires	April-Dec 2015	From the Fairness Commission Evidence Pack, analysis of Parent Carers Questionnaires (in relation to employment)
13. PaCC Survey	April 2015	Survey for PaCC members
14. Comments received from PaCC	Jan 2016	Email with further feedback from PaCC members
15. Email from Alzheimers Society	Jan 2016	Email with services and feedback
16. AMAZE Impact Report 2015	2015	Feedback from users of their services
17. AMAZE Parent Carer Questionnaire	11/12	Analysis of questionnaire
18. AMAZE et al Outreach Disable Children	2012	Evaluation report of partnership outreach to parents/carers of disabled children

19. AMAZE et al Insiders' Guide	2012	Project report for Insiders' Guide, support wellbeing and promote resilience in parent carers
20. AMAZE DLA Project Report	2012	Project report for advisor helping parent carers claim DLA benefits
21. AMAZE Questionnaire on Transition	2014	Questionnaire on Parents experiences of transition
22. AMAZE Impact of having children with special needs	2015	Stats for Fairness Commission, including some local information
23. AMAZE Performance Report	14/15	Details on compass card, information service, DLA service and PaCC
24. AMAZE Performance Report	2014	Details on compass card, information service, DLA service and PaCC
25. Crossroads- demographics and survey	March 2015	Info about people accessing their service (all current clients from April 2014), and survey data (March 2015)
26. Carers Centre- info on carers stars for YP	14/15	Info about carers star and areas of need

11. Appendix B: Summary of Service Mapping

Area	Services
<i>All of Brighton & Hove</i>	DLA Project: Helping parent carers get DLA for child. Volunteers support in family's home.
	Pavilion Families Carers Team (substance misuse)
	Emergency Back Up Scheme (BHCC), 365 days, 24/7
	Carers Centre, bereaved carers' activities, 5x a year, various locations
	Carers Centre, reaching OUT, development and outreach (BME, LGBT, deprived areas, various locations)
	Supported employment team (BHCC), Mon-Fri 9-5
	Huntingdon's disease association, MS society, Motor Neurone Disease Association, Parkinson's Society (all offer support to carers, including some groups and access to funding)
	Adult Social Care, Mon-Fri 9-5, home visits offered outside of these times to meet the needs of carers, carers assessment and support work
	Marlets- support for carers of people with life limiting illnesses, included respite
	Cross Roads, carers respite
	Carers Centre- armed forces development work, various location inc some cross Sussex work
	Free training through BHCC workforce development
	Alzheimer's Society- Home based support with PWD 'respite' for carers, 9-11pm
	Scope Befriending- project using volunteers to support family carers with newly diagnoses disabled child
	Alzheimer's Society- information and support for carers of PWD
	Carers Centre- young carers activities and groups, various locations
	Carers Centre- pharmacy/GP link work, across GP and pharmacy practices, future gap
	Carers Centre- casework and home visits for young and adult carers
	Carers Centre- male carers activities, approx 18 a year
	Carers Centre- engagement work, carer experts, various locations
	MIND- info and advice service, changes ahead- MH carer support, Mon-Fri 9-5
	PACC connects forum for professionals and parent carers
	Carers card offers, for all carers
	The Fed
	Outreach (short breaks)- Seaside View
	Amaze Helpline- information, advice and support to parent carers over phone/email
	Amaze Casework- face to face support on education, health, social care issues for parent carers
	Extra Time
	Barnados link plus
	Mascot
	T21
	Pebbles
Careline and telecare	
BME and disability accessibility research project	
Carers weekend break at Roffey Park, only once a year, adult carers of adults only	
Back care support, Sussex Community Trust, Mon-Fri 9-5	

	Macmillan services (befriending) for people affected by cancer, includes carers, grants.
	Wellbeing Service (primary care), Mon-Fri 8-6, talking therapies
<i>Preston Park</i>	Crossroads Care- supper club, once a month, carer led
	Tudor House- respite centre for CYP with SEND
<i>Central Brighton</i>	Sibling Group- support to siblings of disabled children (time limited project)
	Carers Centre- Monthly EB coffee morning, Emporium London Road
	Choir for parent carers- run by Scope
	Resilience Building (insiders' guide) training for parent carers- community base
	Carers Centre- monthly QP coffee morning
	Alzheimer's Society- Dementia Café, the Level, PWD and carers
	Alzheimer's Society- Singing for brain- PWD and carers, Brighton Museum, Fri pm
	Alzheimer's Society- Carers Support Group (of PWD), 10.30-12.30, Belbourne Court
	Buddhist Centre drop in relaxation class, Thurs
	Looking After You course- relaxation, mindfulness course for parent carers
	Parents with teens get together- for parent carers with teenager young people with SEND, peer support and info
<i>Hove Park</i>	Crossroads Carers Respite (high use of services)
<i>Central/ Goldsmid/ Brunswick</i>	Alzheimer's Society- CRISP, carer's training programme (of PWD)
	Crossroads Carers Respite (high use of services)
	Carers Centre- carers surgeries
	Carers Centre- monthly stroke carers group, Cornerstone Community Centre
<i>North Portslade</i>	Crossroads Carers Respite (high use of services)
<i>South Portslade</i>	Carers Centre monthly coffee morning, Railway Inn
	Crossroads Carers Respite (high use of services)
<i>Hangleton & Knoll</i>	Carers Centre- montly carers coffee morning, Hangleton Manor
	POPP project
	Crossroads Carers Respite (high use of services)
	Alzheimer's Society- dementia café, Hangleton Library, PWD and carers
	Drove Road- respite centre for CYP with SEND, some support for parent carers via respite
	Millview Mental Health carers group monthly
<i>Rottingdean</i>	Carers Centre- monthly Saltdean carers coffee morning, Saltdean Library
<i>Woodingdean</i>	Alzheimer's Society office, carers of PWD, Woodingdean
<i>Moulsecoomb and Bevendean</i>	Alzheimer's Society- dementia café, Bevendean, PWD and carers
	POPP project, Moulsecoomb
<i>East Brighton</i>	Carers Centre- Development work, future gap
	POPP project Whitehawk

12. References

¹ Office for National Statistics. 2011 Census Analysis: Unpaid care in England and Wales, 2011 and comparison with 2001.

² Carers UK. (2015). Valuing Carers 2015: the rising value of carers' support. Available online: <http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015> Accessed 29 Jan 2016.

³ Office for National Statistics. 2011 Census Data. Available online: <http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/guide-method/census/2011/census-data/index.html>

⁴ Age UK, (2016) Invisible army of oldest carers saving state billions: <http://www.ageuk.org.uk/latest-news/invisible-army-of-oldest-carers-saving-state-billions/> Accessed 02/06/2016.

⁵ Projecting Older People Population Information System (POPPI), which uses Office for National Statistics (ONS) population projections. <http://www.poppi.org.uk/> Accessed 02/06/16.

⁶ Brighton & Hove City Council. (2015). Adult Social Care Caring for Others Survey: 2014-15 Results. Available online: <https://www.brighton-hove.gov.uk/sites/brighton-hove.gov.uk/files/Carers%20report%20-%20May%202015.pdf> Accessed 18 Apr 2016.

⁷ The Children's Society. (2013). Hidden from view: The experience of young carers in England. Available online: http://www.childrensociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf Accessed 18 Apr 2016.

⁸ Carers UK. (2015). State of Caring 2015. Available online: www.carersuk.org/stateofcaring Accessed 18 Apr 2016.

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