

## Joint Strategic Needs Assessment 2015-2016

### Executive summary

In Tower Hamlets 19,356 people identified themselves as unpaid carers in the 2011 census. According to the 2011 census a larger proportion of young adults in Tower Hamlets between the ages of 16- 24yrs are delivering higher levels of unpaid care when compared to London or England (38% compared to London 21% and England 14%). Proportionately more men in Tower Hamlets have an unpaid caring role than in London or England. However there are still more unpaid women carers in the borough who also provide significantly more hours of care. The Bangladeshi population is the largest ethnic group in Tower Hamlets providing unpaid care (42%) and provides the highest level of care with 29% delivering over 50 hours per week in the borough.

Being a carer can impact on a person's health and wellbeing through a variety of mechanisms. The national picture for unpaid carers indicates that their health incrementally deteriorates the more hours of care they deliver, with many carers reporting that they have no time to look after themselves. National surveys have documented that taking on a caring role can have significant consequences on an individual's income. Often they have to reduce their working hours or to give up work entirely resulting in serious financial pressures putting additional pressure on an already stressful situation. Surveys of carers repeatedly show that the role compromises their independence and links to social networks which can affect their wellbeing, particularly their mental resilience. At a national level young carers (ie those under 24yrs) are identified to be at serious disadvantage both in the education system and employment when compared to their peers. Many carers report feeling side-lined by health and social care professionals.

The Carers Strategy: 2<sup>nd</sup> Action Plan 2014 -16<sup>1</sup> (DH) recognises the key themes which need to be addressed both nationally and locally to improve the health and wellbeing outcomes for unpaid carers. There is recognition that carers provide significant support to the health and social care system in terms of both quality and economics. Therefore, promoting and addressing carers' needs, to enable their role to continue, is essential. The 2014 Care Act<sup>2</sup>, requires Local Authorities to ensure carers' needs are assessed. NHS England have produced a mandate for all health services/professionals to recognise the importance of carers as partners when making health plans for cared-for patients and to be more aware of the health issues faced by carers themselves<sup>3</sup>.

Valuing Carers 2015<sup>4</sup> reports on the value of the economic contribution carers make in the UK which is estimated at £132 billion per year. This is close to the total annual cost of health spending in the UK which was £134.1 billion in 2014-2015.

### Considerations

A multi-agency Carers' Strategy should be organised in Tower Hamlets to take forward the following considerations which are required to be addressed in the health, social care and education system. The considerations are grouped under the headings taken from the national Carers Strategy (2014-16):

<sup>1</sup> [http://www.mpsv.cz/files/clanky/22729/Strategie\\_pecovatele\\_britanie\\_2014.pdf](http://www.mpsv.cz/files/clanky/22729/Strategie_pecovatele_britanie_2014.pdf)

<sup>2</sup> <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

<sup>3</sup> <https://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

<sup>4</sup> <http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

- 1. Identification and recognition of carers** – there is a large gap between the adults and young carers known to services, particularly those providing long hours of care, and the many reporting caring responsibilities in Tower Hamlets in the 2011 Census. Improvements are required in health, social care and education to systematically identify local carers.
  - 1.1 To continue to build on new approaches in health and social care to recognise carers needs and as partners to be included in the planning and support process.
  - 1.2 To continue to engage carers in the future developments of local health and social care strategies.
  - 1.3 To ensure carers are more systematically included in all care planning processes to reduce the variation in carers' experience across the borough.
  
- 2. Realising and releasing potential** – to identify ways of maintaining adult carers in employment and to enable young carers to reach their potential in the education system and prospects of employment.
  - 2.1 To build on the current school initiative in Tower Hamlets to provide adequate support for young carers.
  - 2.2 To raise awareness with local employers to provide flexibly working practices to support carers to maintain their employment
  - 2.3 To build on schemes to support carers back into employment, particularly when their caring role has ended.
  
- 3. A Life alongside caring** – providing the opportunities for carers to have time outside the caring role to maintain social networks and personal pursuits to sustain their wellbeing.
  - 3.1 To provide accessible and comprehensive information on the availability of the range of services locally to support their role.
  - 3.2 To use the Better Care Fund and other opportunities to provide a range of initiatives to enable carers to have breaks and respite care.
  
- 4. Supporting carers to remain healthy** – to enable carers to access the health promoting initiatives in the borough, access all the national health screening programmes and to access support in primary care if they have a long-term condition.
  - 4.1 To identify carers registered with general practices who have a long-term condition and monitor if they are attending their routine appointments to maintain their health and prevent the onset of complications.
  - 4.2 To identify if carers are being able to access the Public Health initiatives which are being provided in Tower Hamlets.

## 1 Who are carers and what are the issues?

In this fact sheet a carer is defined as someone who spends a significant proportion of their time providing unpaid support to a family member, partner or friend. The reasons someone might require care includes frailty (usually due to old age), learning disabilities, physical disabilities, serious illness, mental health conditions, substance abuse, or a combination of reasons<sup>5</sup>. Within this group there is substantial variability in the complexity and diversity of needs. The carer-cared for relationship can be adult to adult, parent to child (young or adult) or young carer caring for others. Examples of support someone might need from a carer include:

- Moving around the house
- Washing and dressing
- Eating and preparing meals
- Shopping for groceries
- Making telephone calls or filling in forms
- Managing money, such as paying bills
- Taking medicines
- Attending appointments
- Work around the house or garden
- Having someone to talk to

<sup>5</sup> Department of Health (2008) Carers at the heart of 21st Century families and communities: "A caring system on your side. A life of your own"

- Assisting the cared for to plan and order tasks
- Managing the emotional distress of the cared for and their own
- Supporting and protecting someone from harm – particularly in cases where the cared for person have a cognitive impairment or lack of insight.

Some people may need 24 hours care and cannot be left alone; others may require a daily reminder to take medicine, and a weekly food shop; others might be very independent, but need emotional support during times of crisis. It is important to consider the exacerbation of difficulties faced by carers particularly those who are engaged in complex multiple caring roles, caring for more than one person or caring for people with more than one condition or need.

Nationally, approximately one person in ten is a carer which includes young carers<sup>6</sup>. The number of people taking on a caring role is rising all the time, as more people live longer, develop long term conditions, and aspire to maintain independence and control over their lives. The caring relationship is most frequently established within the family, often creating complex interdependencies across generations.

The Health Survey for England 2012<sup>7</sup> provided some useful insights into the nature and extent of caring responsibilities. The survey found:

- Care was most commonly provided to a parent (46% male and 47% female carers) and most particularly by the 45-64 age range (61% male and 60% female carers).
- 22% men and 15% women reported caring for a spouse or partner.
- Caring for a grandparent was relatively common in those aged 16-44yrs (22% men and 17% women).
- The majority of care was provided to someone in a different household (60% men and 67% women).
- Men aged 65 and over were more likely to care for someone in the same household (52%) reflecting that many were caring for a partner. This was less common for women in the same age group (39%) as their caring responsibilities stretched beyond household boundaries.

### **Reported Health/ needs of carers**

The national Carers Strategy (2014-16)<sup>8</sup> uses the 2011 Census data to demonstrate that the general health of carers incrementally deteriorates with the increasing of hours of care provided. The data highlights that 5% of carers reported that their health was 'not good' which rose to 16% amongst those delivering over 50hrs per week of care. The 2011 Census highlighted that young men up to the age of 24yrs caring for over 50hrs a week reported 4 ½ times more poor health than their peers.

The Health and Social Care Information Centre asked adults who provided unpaid care whether their own health had been affected in the last three months by the care they had provided<sup>9</sup>. More women than men said that providing care had impacted on their health (47% and 41% respectively). The most common effects reported were feeling tired (31%), a general feeling of stress (29%), disturbed sleep (22%) or feeling short tempered (20%).

Over three quarters (76%) of carers responding to the Carers UK<sup>10</sup> (2014) survey were concerned about the impact of caring on their health over the next year. Concern with lack of sleep was again common, with 69% finding it difficult to get a good night's sleep. 58% reported reducing exercise since they started caring and 45% reported that maintaining a balanced diet was difficult. 73% reported increased anxiety, 82% increased stress and 50% stated they were affected by depression<sup>7</sup> after taking on a caring role.

The survey found many carers find it difficult to maintain relationships and social networks. 57% lost touch with friends or family. Losing the support of friends and family can have a big impact on a carer's resilience, yet without more practical support and time away from caring, carers are not able to benefit from emotional support from others. When

<sup>6</sup> National Statistics (based on 2011 Census).

<sup>7</sup> <http://www.hscic.gov.uk/catalogue/PUB13218/HSE2012-Sum-bklet.pdf>

<sup>8</sup> [http://www.mpsv.cz/files/clanky/22729/Strategie\\_pecovatele\\_britanie\\_2014.pdf](http://www.mpsv.cz/files/clanky/22729/Strategie_pecovatele_britanie_2014.pdf)

<sup>9</sup> <http://www.hscic.gov.uk/catalogue/PUB19295/HSE2014-ch6-soc-care-prov.pdf>

<sup>10</sup> <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2014>

asked how they thought society views those providing unpaid care, less than 10% of carers thought they were regarded as making a valuable contribution. Half of carers felt that society does not think about them at all.

Using information from the Personal Social Services Survey of Adult Carers in England (2012-13) the Carers Strategy reports that the highest level of needs were reported among carers with mental health problems of their own, among carers from Asian/British Asian communities, among carers under 64 years and amongst those who have been caring for 15 –20yrs. Taken from the Survey of Carers in Households in (2009/10) the Carers strategy reported that a vast majority of carers were not in touch with social care and only 6% of carers had been offered a carer assessment.

### **Economic Activity**

NIHR School for Social Care<sup>11</sup> found only 12% women and 9% of men providing care are maintaining full-time employment. In 2011 this research found that the key threshold when a carer is at risk of leaving employment is when care is provided at 10 hours or more a week, which is a lower threshold than previously thought. Since the publishing of these findings and recognition of the issues of financial hardship for experienced by carers, a governmental task and finish group was set up to produce recommendations on supporting carers in employment<sup>12</sup>.

Carers UK<sup>13</sup> surveyed over 4000 carers in 2014. Over half (55%) of carers reported that they are worried about the impact of cuts to care and support services over the next year. Many continue to experience severe strain on their finances and ability to afford even the essentials. More than half (54%) of carers are struggling to pay household bills or to make ends meet suggesting continued pressure on carers' finances. Large numbers of carers continue to cut back on these essentials. Over a third (35%) of all carers responding to the survey are cutting back on food and heating.

The Health and Social Care Information Centre in 2014 when surveying adult carers up to the age of 64yrs found the most frequently mentioned impact on their work situation was working fewer hours (7% of men and 8% of women)<sup>14</sup>.

### **Economic Value of Carers**

Valuing Carers 2015<sup>15</sup> reports on the value of the economic contribution carers make in the UK which is estimated at £132 billion per year. This is close to the total annual cost of health spending in the UK which was £134.1 billion in 2014-2015. The carers' economic contribution is growing with the 2015 figures 7% higher than the figure for 2011. This mainly accounts for carers providing more hours of care (82%), and partly due to the increased hourly cost of paid homecare (18%). The figures mean that, in 2015, the value of the contribution made by the UK's carers saves the public purse enormous sums every week, day and hour of the year:

- £2.5 billion per week
- £362 million per day
- £15.1 million per hour

### **Young Carers**

Young Adult Carers and Employment<sup>16</sup> report demonstrated that 2011 Census identified more than 375,000 young adult carers in the UK aged 14–25 who are providing support and assistance to their families and friends. For young carers the transitions from childhood into adulthood were especially complex and challenging.

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<sup>11</sup> [http://www.sscr.nihr.ac.uk/PDF/Findings/Findings\\_10\\_carers-employment\\_web.pdf](http://www.sscr.nihr.ac.uk/PDF/Findings/Findings_10_carers-employment_web.pdf)

<sup>12</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/232302/Supporting\\_Working\\_Carers\\_Summary\\_accessible.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/232302/Supporting_Working_Carers_Summary_accessible.pdf)

<sup>13</sup> <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2014>

<sup>14</sup> <http://www.hscic.gov.uk/catalogue/PUB19295/HSE2014-ch6-soc-care-prov.pdf>

<sup>15</sup> <http://www.carersuk.org/for-professionals/policy/policy-library/valuing-carers-2015>

<sup>16</sup> [https://www.carers.org/sites/default/files/young\\_adult\\_carers\\_and\\_employmentlo\\_final\\_2.pdf](https://www.carers.org/sites/default/files/young_adult_carers_and_employmentlo_final_2.pdf)

The difficulties young carers experience as a result of their caring role can have significant negative impacts on their engagement with education and employment and on their overall physical and emotional wellbeing. More information is required to understand how their caring roles impacts upon their working lives or how it may prevent them from having working lives, so that appropriate services and support can be developed and provided for them.

## 2 What is the policy context?

### National:

#### **The Care Act 2014<sup>17</sup>:**

The central theme of this Act is to consider both the needs of cared for and the needs of individuals who provide the care (carer) on a regular basis. This<sup>7</sup> recognises the role of carers as an intrinsic part of care and support, and that their well-being is equally as important as that of the person cared for.

One of the key elements of the 2014 Care Act, when focusing on carers<sup>2</sup>, is that it places a duty of care on local authorities to identify carers with unmet needs within their local population. As part of their wider responsibilities local authorities are to make provision to intervene to prevent and or delay the development of needs. There is a requirement for local authorities to undertake a formal carer's assessment where it appears that a carer may have needs for support at any level.

Local authorities are required by the Care Act, when assessing an adult's need for care and support, to involve the carer in the assessment and to ensure a written outcome of the assessment is provided to the carer as well as to the individual who requires care.

Under the Care Act local authorities are required to establish and maintain a service to provide information and advice to its local population which relates to care and support for adults including support for carers. Local authorities are particularly tasked with providing information and advice on how the care and support system works locally including the types of care and support available and the choice of local providers with details on how to access these.

The Care Act requires local authorities to promote the integration of care and support with the local health services to promote the well-being of adults with care and support needs, and of carers, to prevent or delay the onset of needs or to improve the quality of care and support being delivered. The Better Care Fund has been established by the Government to facilitate better integration within the system and provide breaks for carers where appropriate.

#### **Carers Strategy : Second National Action Plan 2014-16<sup>18</sup>:**

The Carers Strategy promotes 4 priority areas:

- Priority 1 :Identification and recognition; of carers by supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution by involving them from the outset in designing local provision and when introducing local care packages.
- Priority 2: Realising and releasing potential; enabling those with caring responsibilities to fulfil their education and employment potential.
- Priority 3: A life alongside caring; personalised support for both carers and those they support, enabling them to have a family and community life
- Priority 4: Supporting Carers to stay healthy; supporting carers to remain mentally and physically well.

There is an action plan at the end of this document stating the main initiatives taking place in Tower Hamlets under the 4 priority action areas.

<sup>17</sup> <https://www.gov.uk/government/publications/care-act-2014-part-1-factsheets>

<sup>18</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/368478/Carers\\_Strategy\\_-\\_Second\\_National\\_Action\\_Plan\\_2014\\_-\\_2016.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/368478/Carers_Strategy_-_Second_National_Action_Plan_2014_-_2016.pdf)

### **NHS England's Commitment to Carers 2014<sup>19</sup>:**

Recognising the importance of carers as an asset to the NHS and following an engagement exercise with carers organisations, carers and other key partners the following emerging themes are contained in the document some which are similar to those found in the Carers Strategy and include:

- Raising the profile of carers – recognising and considering carers in health
- Education, training and information- including sharing best practice models of care
- Service development – ensuring all health services start to work with needs of the carers
- Person centred well-coordinated care- recognising the role of carers in personalised care planning
- Primary care – to increase the identification of carers
- Commissioning support –working with carers to recognise best practice to improve commissioning
- Partnership links: to engage with partners to build effective ways of working
- NHS England as an employer: to implement employment practices to support carers in the workforce.

### **The Children and Families Act 2014<sup>20</sup>:**

Section 96 of the Children and Families Act provides the definitions of a young carer as a person under 18 who provides care for another person of any age, except where that care is provided for payment, pursuant to a contract or voluntary work.

The Act states that all young carers under the age of 18 have a right to an assessment regardless of whom they care for, what type of care they provide or how often they provide it. A young carer has the right to an assessment based on the appearance of need – which means that young carers will no longer have to request an assessment or be undertaking a 'regular and substantial' amount of care. However a young person does still have the right to request an assessment.

#### **Local:**

#### **Adult Carer Plan 2015 – 2016<sup>21</sup>:**

This is an interim plan before the publication of the 2016-2019 Plan for Carers. Whilst the focus of this plan is adult social care, it has clear links with the Tower Hamlets Clinical Commissioning Group for local health services and with the third sector. The plan sets out how Tower Hamlets council will meet the requirements of the 2014 Care Act which strengthens the rights and recognition of carers in the social care system.

The Adult Carer's Plan includes sections on :

- Carers assessments
- Care plans and personal budgets
- Local options and support for Carers
- Results of the 2013/14 local users survey

#### **The Memorandum of Understanding (MOU) for young carers March 2015**

The basis for the local MOU used the national template<sup>22</sup> to help promote the collaboration between Adult's and Children's social care services in the local borough and to enhance partnership working with health and third sector partners. The memorandum applies to anyone up to the age of 25yrs and includes the transition from children services to adult services for care and support.

<sup>19</sup> <https://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

<sup>20</sup> <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

<sup>21</sup> <http://www.towerhamlets.gov.uk/Documents/One-TH/2015-16-Strategic-Plan.pdf>

<sup>22</sup> [http://adcs.org.uk/assets/documentation/No\\_wrong\\_doors\\_Young\\_Carers\\_Memorandum\\_of\\_Understanding\\_2015.pdf](http://adcs.org.uk/assets/documentation/No_wrong_doors_Young_Carers_Memorandum_of_Understanding_2015.pdf)

The sections include:

- The key principles of working with young carers
- Defining and identifying young carers
- Provision of assessments
- Provision of information, advice and advocacy
- Transition to adulthood
- Safeguarding
- Local partnerships

### The Better Care Fund<sup>23</sup>

This fund was announced in the June 2013 spending round and is aimed at ensuring the transformation to integrate health and social care. The budget which has been set in July 2016 of £21.46million is to be shared between health and social care to enable the local services to work more closely together. Tower Hamlets council and Tower Hamlets CCG (Clinical Commissioning Group) have committed to improving the levels of working together including jointly commissioning local services, better data sharing, seven day working across health and social services and the protection on social care services.

## 3. What is the local Picture

### Results from the 2011 Census

The first part of this section will focus on the 2011 census results to obtain the local picture in Tower Hamlets and compare these results to the averages found across London and England.

The 2011 Census identified 19,356 unpaid carers in Tower Hamlets representing 7.6% of the local population which is lower than the overall percentage of unpaid carers in London (8.4%) and England (8.4%). However when compared to London and England averages, Tower Hamlets has a higher proportion of residents providing more hours of caring support: 18.1% provide 20-49 hours of care per week, and 25.4% provide more than 50 hours of care, as indicated in Table 1.

**Table 1 Provision of hours of care**

	Tower Hamlets (No.)	Tower Hamlets	London	England
<b>Residents providing unpaid care</b>	19,356	100.0	689,973	5,430,016
% of carers providing 1 to 19 hours a week	10,931	56.5	63.1	63.6
% of carers providing 20 to 49 hours a week	3,510	18.1	15.3	13.3
% of carers providing 50 or more hours a week	4,915	25.4	21.6	23.1

Source: 2011 Census (KS301EW)

**Table 2: Age of carers, 2011**

Age	Tower Hamlets		London		England	
	Number	%	Number	%	Number	%
<b>All Ages</b>	<b>19,356</b>	<b>100</b>	<b>689,973</b>	<b>100</b>	<b>5,430,016</b>	<b>100</b>
Age 0 to 15	567	2.9	17,381	2.5	111,423	2.1
Age 16 to 24	2,795	14.4	54,577	7.9	302,356	5.6
Age 25 to 34	4,737	24.5	93,741	13.6	473,891	8.7
Age 35 to 49	5,681	29.4	204,950	29.7	1,420,318	26.2
Age 50 to 64	3,915	20.2	207,171	30.0	1,929,420	35.5
Age 65 and over	1,661	8.6	112,153	16.3	1,192,608	22.0

Source: 2011 Census (LC3304EW)

<sup>23</sup> <http://www.local.gov.uk/documents/10180/5572443/Better+Care+Fund+Planning+Requirements+for+2016-17+Technical+Guidance+Annex+4/95d68c2e-8e5f-4ff0-9d5b-0478cd79d118>

Table 2 indicates that Tower Hamlets has a higher proportion of carers in the younger age groups than in London and England. This is particularly pronounced in the 16 – 34yrs age group which make up 38.9% of the total caring population in Tower Hamlets as compared to 21.5% in London and 14.3% in England. This is reflective of the relatively young population within the borough. More analysis on the 0 -24yrs age group will be found at the end of this section.

The following tables 3 -5 focus on the numbers of hours being provided by the different age groups of carers in Tower Hamlets compared to those in London and England. The percentages circled in red demonstrates where significant higher levels of care in that age group are being delivered in Tower Hamlets when compared to London and England, and reemphasises that relatively younger people are taking on more caring responsibilities.

**Table 3: Hours of provision of Care : 1 – 19 Hours in age groups**

Area	All ages	0-15	%	16-24	%	25-34	%	35- 49	%	50-64	%	65 +	%
Tower Hamlets	10,931	446	4.1	1,910	17.5	2,925	26.8	3,032	27.1	1,984	18.2	634	5.8
London	435,278	13,737	3.2	39,236	9.0	60,552	13.9	127,348	29.3	137,998	31.7	56,407	13.0
England	3,452,636	90,171	2.6	219,853	6.4	300,162	8.7	917,535	26.6	1,341,380	38.9	583,535	16.9

Source: 2011 Census (LC3304EW)

**Table 4: Unpaid care: 20 - 49 Hours**

Area	All ages	0-15	%	16-24	%	25-34	%	35- 49	%	50-64	%	65 +	%
Tower Hamlets	3510	55	1.6	508	14.5	901	25.7	1088	31	676	19.3	282	8
London	105,339	1,841	1.7	9075	8.6	16,871	16	33,534	31.8	29,106	27.6	14,972	14.2
England	721,143	11,142	1.5	47,962	6.7	74,098	10.3	199,118	27.6	237,760	33	151,063	20.9

Source: 2011 Census (LC3304EW)

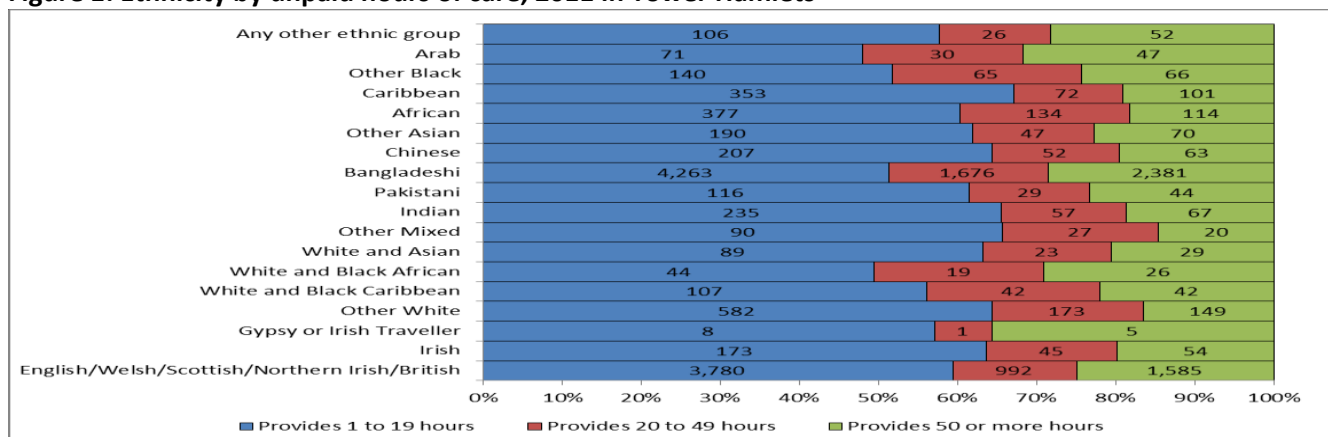
**Table 5: Unpaid care: 50 + Hours**

Area	All ages	0-15	%	16-24	%	25-34	%	35- 49	%	50-64	%	65 +	%
Tower Hamlets	4917	66	1.3	377	7.7	911	18.5	1561	31.8	1255	25.5	745	15.2
London	149,296	1,803	1.2	6,266	4.2	16,318	10.9	44,068	29.5	40,067	26.8	40,774	27.3
England	1,256,237	10,110	0.8	34,541	2.7	99,631	7.9	303,65	24.2	350,280	27.9	458,010	36.5

Source: 2011 Census (LC3304EW)

Tables 3 and 4 indicate that in Tower Hamlets the percentages of 16 – 34yr olds carers providing between 1 – 19 hours and 20 – 49 hours of care are twice as high as the averages across England and significantly higher than the averages in London. Table 5 demonstrates that in 2011 in Tower Hamlets the percentage of 25 – 34yrs providing over 50 hours of care were significantly higher than the averages found for London and England.

**Figure 1: Ethnicity by unpaid hours of care, 2011 in Tower Hamlets**



Source: 2011 Census (DC2301EW)



Figure 1 provides an ethnic group breakdown of those providing unpaid care in Tower Hamlets and the hours of care provided. Around 42.9% (8,320) of those providing unpaid care are from the Bangladeshi population. Of carers from the Bangladeshi population around 2,381 representing 29% are delivering more than 50 hours of care compared to 1,585 representing 25% of the White British carers in Tower Hamlets.

Of 19,356 carers in Tower Hamlets, White British account for 32.8% (6,357) and are the next largest ethnic group to provide unpaid care which is far below the London and England averages of 52.2 % and 85.6% respectively however this is representative of the boroughs current population.

**Table 6: Unpaid care by gender in Tower Hamlets compared with London and England, 2011**

Sex	Tower Hamlets	%	London	%	England	%
All Persons	19,277	100	687,383	100	5,409,433	100
Males	8,524	44.2	292,419	42.5	2,285,192	42.2
Female	10,753	55.8	394,964	57.5	3,124,241	57.8

Source: 2011 Census (LC3301EW)

Table 6 highlights that amongst the Tower Hamlets carers' population women provide a greater amount of unpaid care 55.8% compared to the 44.2% of men. However this is slightly lower than averages for women across London (57.5%) and England (57.8%). In Tower Hamlets a higher percentage of men (44.2%) are carers as compared to London (42.5%) and England (42.2%) averages.

**Table 7: Unpaid care by gender by hours of provision, in Tower Hamlets 2011**

Sex	Provides unpaid care: Total	%	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	%
All persons	19,277	100	10,867	100	3,496	100	4,914	100
Males	8,524	44	5,322	49	1,526	44	1,676	34
Females	10,753	56	5,545	51	1,970	56	3,238	66

Although more men proportionately provide care in Tower Hamlets than in London and England, when this is broken down further into the provision of hours of care, Table 7 demonstrates that the percentage of women providing 50 hours or more care per week are significantly higher providing 66% of this provision as compared to 34% of men.

The 2011 Census highlights that women in Tower Hamlets on average are providing more hours of care than the London and England with around 17% per cent of female carers are providing 50 or more hours of care per week compared to 14% in London and England.

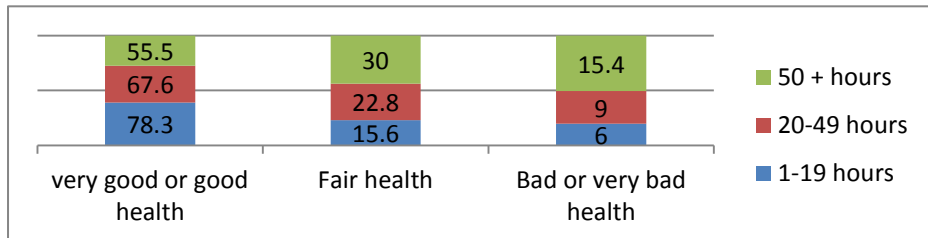
**Table 8: Health of unpaid carers in Tower Hamlets and compared with the health of carers in England and London, 2011**

General Health	Tower Hamlets	%	England	%	London	%
Total Carers	19,356	100	5,430,016	100	689,973	100
Very good health	6162	31.8	1,674,171	30.8	226,440	32.8
Good health	7462	38.6	2,237,790	41.9	284,229	41.2
Fair health	3981	20.6	1,124,762	20.7	134,981	19.6
Bad health	1410	7.3	294,759	5.4	35,885	5.2
Very bad health	341	1.8	62,534	1.2	8,438	1.2

Source: 2011 Census (DC2301EW)

According to the 2011 Census a majority of the borough's residents had very good or good health (83 %) but for those providing care this fell to 70.4% per cent. Table 8 demonstrate in Tower Hamlets 9% of carers reported having bad or very had health compared to 6% in the wider population. This was also significantly higher than London (6.4%) and England (6.6%). This confirms the need to focus on the health of carers in the Tower Hamlets population.

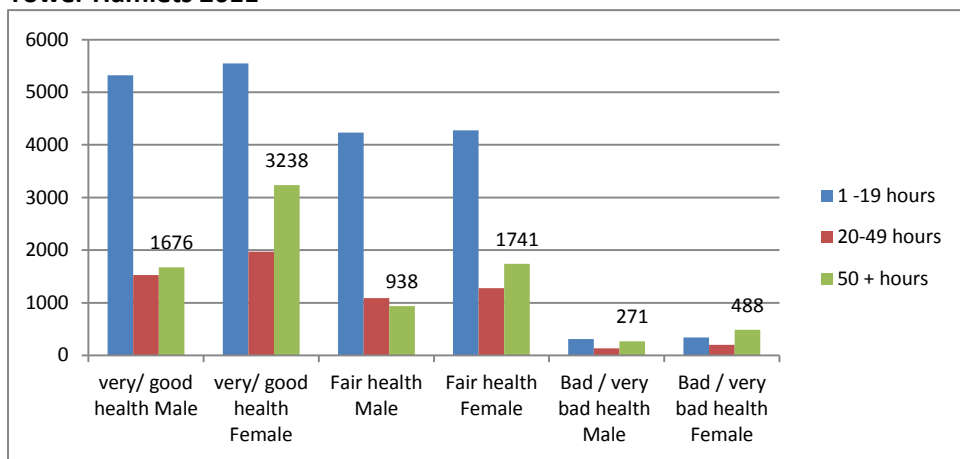
**Figure 2 : Reported health of the carers in Tower Hamlets in percentages compared to the number of hours of care delivered**



Source: 2011 Census (LC3301EW)

Figure 2 indicates that providing more hours of care leads to carers experiencing more ill health. This is particularly pronounced in those providing 50 hours or more of care who report significantly higher rates of bad or very bad health.

**Figure 3 : A comparison of reported health amongst male and female carers in relation to hours of care provided in Tower Hamlets 2011**



Source: 2011 Census (LC3301EW)

Figure 3 indicates that amongst women and men carers in Tower Hamlets there are similar patterns when reporting on their health and the corresponding hours of care up to 49 hours. However for those providing over 50hrs of care 20% of men as compared to 30% of women reported good to very good health. A further 47.4% of women carers compared to 37% of men carers are reporting bad to very bad health.

**Table 9 Economic activity of carers in Tower Hamlets compared to London and England, 2011**

	Tower Hamlets	%	London%	England%
All economic activity	18,789	100	100	100
Total economically active	10,718	57	62	58
Total in employment	8,970	48	56	54
Unemployed	1,748	9	6	4
All economically inactive	8071	43	38	42
Retired	1,891	10	18	27
Student (including full time)	996	5	4	2
Looking after home or family	3,316	18	10	8
Long-term sick and disabled	1,006	5	4	4
Other	862	5	3	2

Source: 2011 Census (LC3301EW)

In 2011 fewer carers in Tower Hamlets were economically active than the regional and national average (57.6% compared to the London rate of 62.4% and 62.1% in England. A higher proportion of the borough's carers are unemployed 9% when compared to 6% in London and 4% in England. The slightly higher rates of economic inactivity among carers in the borough can be largely attributed to the 18% of carers looking after a home and family compared to 10% in London and 8% in England.

**Table 10 :Residents in Receipt of Carers Allowance by age and gender, August 2015**

Age	Male	Female	Total	Male%	Female%	Total
Aged 18-24	90	140	220	41	64	5
aged 25-29	90	340	440	20	77	9
Aged 30-34	100	520	620	16	84	13
Aged 35-39	130	580	700	19	83	15
Aged 40-44	190	490	680	28	72	15
Aged 45-49	170	460	640	27	72	14
Aged 50-54	170	370	540	31	69	12
Aged 55-59	140	300	440	32	68	9
Aged 60-64	100	160	260	38	62	6
Aged 65 and over	20	130	150	13	87	3
Total	1,200	3,490	4,680	26	75	100

Source: ONS/NOMIS (DWP Working Age Benefits, August 2015)

Table 10 is highlighting that 4,680 of carers in Tower Hamlet are receiving carer's allowance. This can be received in the following circumstances:

- spending at least 35 hours a week caring for a disabled person - you don't have to live with them
- caring for someone who receives the higher- or middle-rate care component of Disability Living Allowance, either rate if Personal Independence Payment daily living component, or any rate of Attendance Allowance
- not earning more than £110 a week (after deductions)
- not being in full-time education

Information from the Tower Hamlets Carers Centre indicates that since the introduction of the new carers assessment 358 have completed the assessment with support from the Carers Centre staff and they are aware of 4 carers who completed the assessment on line. Of these 92 of the applications were referred to the local authority assessment team for further social care interventions including financial support.

#### **Results of the local Carers Survey (2014-15) in Tower Hamlets<sup>24</sup>**

The Carers Survey is organised on a 2 yearly basis nationally and in Tower Hamlets 965 carers were targeted representing those who had received a carer's assessment in the previous 12 months. The results of the local Carers Survey will be compared with the National Carers Survey of 2014/15<sup>25</sup>. Of the 965 carers in Tower Hamlets forwarded the questionnaire 283 completed by October 2014 (29% response rate). Across the country (for 2014/15) the response rate was higher at 44%.

It should be noted that the survey has a margin of error around the results of no more than +/- 5%. However response to the 2012-13 Carer Survey was considered too small to be included in the Department of Health Adult Social Care Outcomes Framework, so the results need to be interpreted with caution

<sup>24</sup>

<sup>25</sup> <http://www.hscic.gov.uk/catalogue/PUB18423/per-soc-ser-sur-ad-car-eng-2014-15-rpt.pdf>

The themes arising from the 2014 - 15 survey for Tower Hamlets were :

- The impact of caring on their quality of life – which is based on responses to questions relating to feeling safe, ability to take care of themselves, getting enough encouragement and support, social contact, control over daily life and ability to do things valued and enjoyed.
- A carer’s access to information, advice and quality of support (to be covered in section 8)

**Figure 4 : Quality of life report from the Carers Survey 2012/13 & 2014/15 compared to local service user survey 2013/14**

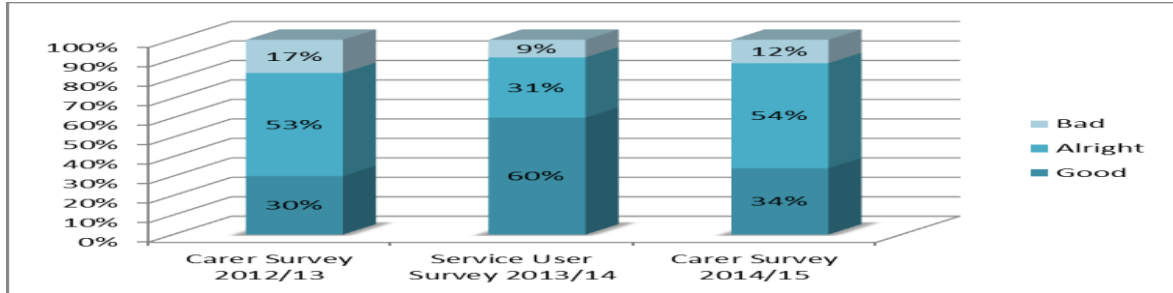
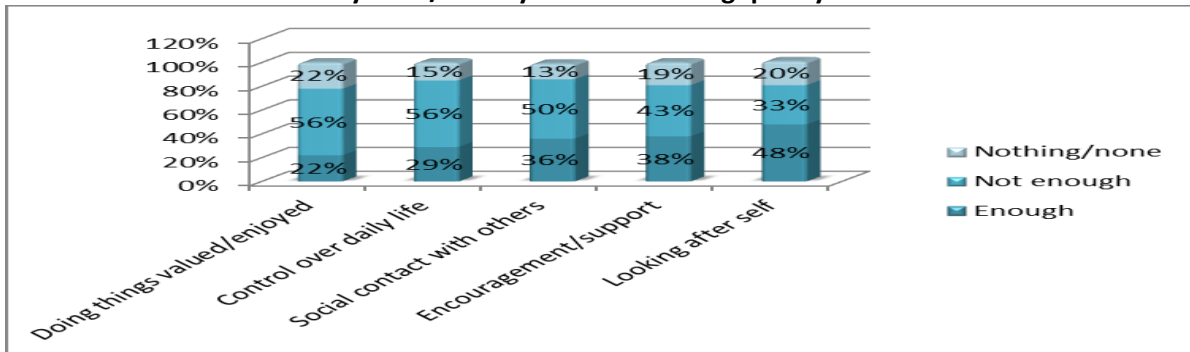


Figure 4 indicates that there has been some improvement from the carer’s survey between 2012/13 and 2014/15 in their quality of life. However there is striking difference in Figure 4 when comparing the quality of life for those being cared for (service users) which is the central column who have a much higher rate of satisfaction with 60% reporting a good quality of life in 2013/14 compared to only 34% of carers in 2014/15

**Figure 5 : Tower Hamlets Carers Survey 2014/15- key factors effecting quality of life**



Although the quality of life indicators for carers have been shown to be making a slight improvement in Tower Hamlets, Figure 5 demonstrates that 65% of the carers who completed the survey do not do enough things they value or enjoy compared to 61% from national survey results, 56% in Tower Hamlets do not have enough control over their daily lives compared to 61% in the national survey and only 48% reported having enough time to look after themselves in contrast to 58% in the national survey for 2014/15. In Tower Hamlets 50% reported not experiencing enough social contact with others as compared to 47% in the national survey. Ad hoc meetings with carers further supports this evidence that in Tower Hamlets carers continue to report a poor quality of life, due to a combination of their own ill health, tiredness, loss of friends, lack or loss of income and people with whom to share their concerns.

Information from previous Carers survey (2013/14) but not specifically asked in the 2014/15 found:

- Carers in Tower Hamlets experience more financial difficulties as a result of caring than the national average. Fifty one percent (51%) of carers surveyed in Tower Hamlets reported some or a lot of financial difficulties, compared to 40% surveyed in England as a whole.
- Around 7% of carers surveyed look after more than one person in Tower Hamlets which is similar to national figures. However, carers in Tower Hamlets are more likely to live with the person they care for (84% in Tower Hamlets, compared to 73% England average).

**Data from General Practice** – Recording if someone is a carer on general practice records has been poor and more work is required locally to improve this situation. Currently using information from the GP practice records (July 2016) 13% (40,864) of patients have been asked about their carers status and 8% (8862) confirmed they were a carer.

Currently there is no breakdown of the reasons for adults being cared-for in Tower Hamlets apart from information from the Carers Centre data which is contained in Section 5 of this document.

**Young Carers**

It is important to specifically look at the statistics for young carers in Tower Hamlets who were identified in the 2011 census data as many were or still at school or going through the transition period from childhood to adulthood.

**Table 11: Numbers of young carers up to age 24yrs in Tower Hamlets and the hours of care provided compared to London and England (2011)**

	1 hour – 19 hours				20 hours -49 hours				50 hours +			
	0-15	%	16-24	%	0-15	%	16-24	%	0-15	%	16-24	%
Tower H	446	4.1	1,910	17.5	55	1.6	508	14.5	66	1.3	377	7.7
London	13,737	3.2	39,236	9.0	1,841	1.7	9075	8.6	1,803	1.2	6,266	4.2
England	90,171	2.6	219,853	6.4	11,142	1.5	47,962	6.7	10,110	0.8	34,541	2.7

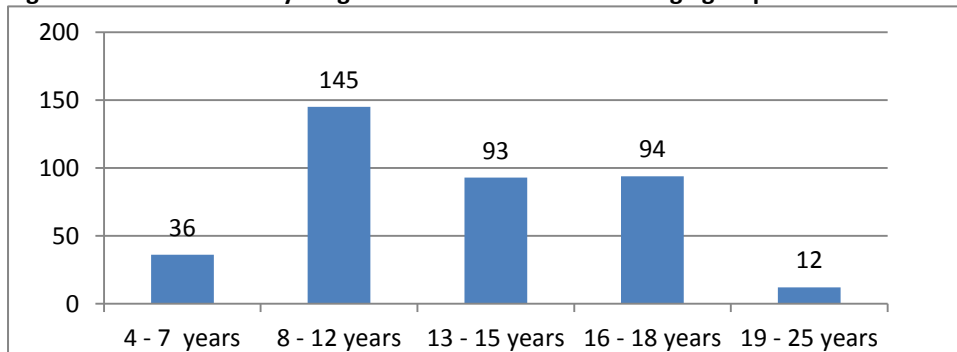
Source: 2011 Census (LC3301EW)

Table 11 indicates that 3362 young carers were identified in the 2011 census. When compared to London and England a much higher proportion of young people in Tower Hamlets are providing care. It should however be noted that young carers formally classified up until the age of 18 years, so only a proportion of 31.7% of the carers aged 16 -24yrs delivering care for over 20 hours will be categorised as young carers.

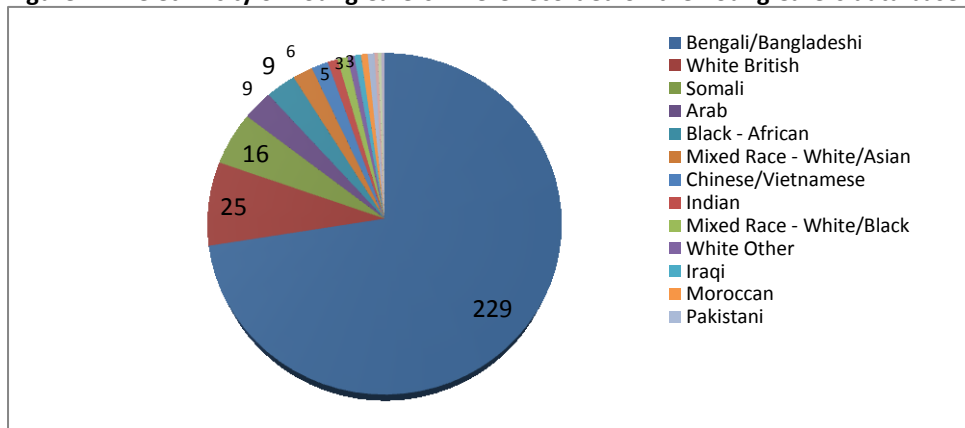
Currently there are only 380 young carers are known to social care in the council, suggesting considerable under-ascertainment of support requirements.

The following data is using information directly from the Young Carers data base which is held in Tower Hamlets council.

**Figure 6 The numbers of young carers in Tower Hamlets in age groups where known**



**Figure 7. The ethnicity of Young Carers where recorded on the Young Carers data base with Tower Hamlets council**



**Table 12 Reasons for care where recorded being delivered by Young Carers**

Parent with mental illness	294
Parent with a substance misuse	7
Parent with a physical disability	1
<b>Total</b>	<b>302</b>

Table 12 is highlighting that young carers in Tower Hamlets supporting parents with physical disabilities are underrepresented in this table. The numbers of young carers being reported in Table 12 as supporting parents with mental illness could coincide with a project organised by CHAMP's which when working with adults with mental health problems started to highlight where children under 18yrs were providing carer support in the home.

#### **4. What are the effective interventions?**

The Carers Strategy: Second National Action Plan<sup>26</sup> builds on the previous government document Carers at the Heart of 21<sup>st</sup> Century and Communities (2008)<sup>27</sup> and highlights the steps required to improve and support the health and wellbeing of carers. These have been set out under the following priority areas:

##### **1. Identification and Recognition of Carers**

Carers should be encouraged to identify themselves as carers at an early stage facilitating access to information and advice to provide support for this role. Carers should feel that their knowledge and experience is valued by health and social care professionals and are consulted in developing local strategies.

Information and advice is needed to address different aspects of caring at different times. Recognising that the caring landscape is constantly changing with approximately 2 million leaving and joining the role every year needs to influence how new carers are informed of current local services and support.

Introduction of the Care Act (2014) has strengthened the need for carers to be identified in local areas and for both the health services and local authorities to cooperate to identify and to provide support for the unmet need of carers. The vision set out in Transforming Primary Care<sup>28</sup> encourages primary care to improve the identification of carers at practice level.

There is a pledge for more training and awareness amongst all health professional in the NHS Commitment to Carers. This document recognises the need for carers to be identified and to recognise them as individuals with their own need, choices and aspirations. In the Mandate to NHS England<sup>29</sup> there is a commitment to ensure that the NHS becomes significantly better at involving patients with their carers'.

##### **1.1 Identification and Recognition Young Carers**

Money was released from the Department of Education between 2011 and 2015 to increase the identification of young carers and to provide them with the support required. There is to be a national research project to develop a more reliable estimate of the numbers of young carers across the country and to more fully understand the impact on these young people both in terms of health and educational attainment.

<sup>26</sup> [http://www.mpsv.cz/files/clanky/22729/Strategie\\_pecovatele\\_britanie\\_2014.pdf](http://www.mpsv.cz/files/clanky/22729/Strategie_pecovatele_britanie_2014.pdf)

<sup>27</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/136492/carers\\_at\\_the\\_heart\\_of\\_21\\_century\\_families.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136492/carers_at_the_heart_of_21_century_families.pdf)

<sup>28</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/304139/Transforming\\_primary\\_care.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/304139/Transforming_primary_care.pdf)

<sup>29</sup> <https://www.gov.uk/government/publications/nhs-mandate-2016-to-2017>

## **2. Realising and Releasing Potential**

Enabling young and adult carers to fulfil their educational and employment potential. A recent report from the Carers Trust and Nottingham University<sup>30</sup> which involved 300 young carers, 42% reported that their role was not recognised at the school so no support was offered and a quarter reported bullying because of their caring role.

The Children and Families Act 2014 sets out how young carers' assessments should be carried out with particular attention to what support can be provided to enable them to participate in education or training. An updated e-learning programme which was launched in 2011 has been produced by the Department of Education<sup>31</sup> to enable the schools to identify and support young carers.

Supporting carers to maintain employment or to return to work is recognised as a challenge but has a significant benefit to the carers themselves, employers and the economy. Of the 5000 respondents to the Carers UK State of Caring Survey in 2013<sup>32</sup> who had reduced their hours, given up work or retired early due to their caring role 25% did this as the cost of replacement care was too high, 23% because services were not flexible enough and 25% reported that they were not offered support through work.

The government has committed under the Carers Strategy to continue to explore ways of increasing flexible working opportunities following the rights of all employees to request flexible working arrangements as from the 30<sup>th</sup> June 2014<sup>33</sup>

## **3. A life alongside caring**

Carers should be enabled to have a family and community life though personalised support for both themselves and the people they care for recognising that individual carers' circumstances do vary enormously. Many carers particularly women are part of a 'sandwich' generation in which they face competing demands from both older and younger family members. A Carers UK report highlighted that in the UK 28% of grandparents with grandchildren under the age of 16yrs have one parent who is alive.

Under the new Care Act the rights of carers are now equivalent to those who are being cared for. The requirement to integrate health and social care services to improve the well-being of adults with care needs is being seen as a positive step to improve the carers' situation. The establishment of the Better Care Fund was intended to support the new working practices and to shift the emphasis onto more preventive care. Money from this fund is to be used to provide more carers breaks where appropriate and for assessments for carers.

The Carers Strategy highlights that more information is required to evidence the impact of the caring role on people's broader circumstances. The government has tasked the Department of Health and Department for Work and Pensions to review the evidence to provide a better understanding of carers across a range of outcomes which could be utilised for future policy changes.

## **4. Supporting Carers to stay Healthy**

While caring can be very rewarding and fulfilling it is recognised that it can also be emotionally and physically draining. Many carers can experience significant stress caused by the extent and nature of their caring responsibilities, balancing this with education or paid employment, the state of their finances and concerns about the quality of care provided by others. As previously highlighted those caring for more than 50hrs per week are five times more likely to report they are not in good health than their peers without caring responsibilities.

<sup>30</sup> [https://www.carers.org/sites/default/files/young\\_adult\\_carers\\_and\\_employmentlo\\_final\\_2.pdf](https://www.carers.org/sites/default/files/young_adult_carers_and_employmentlo_final_2.pdf)

<sup>31</sup> <http://www.childrenssociety.org.uk/sites/default/files/Young-Carers-Web-Pub-v13/player.html>

<sup>32</sup> <https://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2015>

<sup>33</sup> <https://www.gov.uk/flexible-working/overview>

Recognising that it is important for carers to be supported to attend for any routine appointments to look after any long-term conditions they may have, to attend any screening and health checks offered to continue to maintain their health. Carers can also need the support to pursue leisure and sport activities, to have access to any of health promoting activities offered through the local NHS and local authorities in order to maintain their health and wellbeing. The Carers Strategy states that nationally an offer of health checks for carers is going to be introduced for those caring for people with dementia as part of the GP Enhanced Service. Carers would benefit from accessing a wide range of support including stress management, relaxation classes and psychological therapies to maintain their emotional resilience.

The Carers Strategy recognises that for those who have lost the person/s they are caring for this can induce poor physical and mental health which could require bereavement counselling together with support to cope with the end of their caring role. NHS England's new ambitions for End of Life Care<sup>34</sup> will include intentions for support of bereaved carers. For more information: JSNA End of Life Factsheet<sup>35</sup>

### **Support for young carers**

The following recommendations come from the Young Carers and Employment document<sup>36</sup> (2014). Young adult carers need to be identified as early as possible. To receive a regular assessments and review of their own needs to ensure that their caring role does not have a negative impact on their education, health and wellbeing. The document recognises that schools should establish a clear framework of support for young carers with leads to provide this support. Targeted career advice should explore all options and encourage young people to identify the transferable skills from their caring role and use them to their advantage in the workplace.

Early intervention is needed to identify young adult carers at college and university who are in danger of dropping out or not fulfilling their potential, and to provide them with appropriate support in good time. Employers, apprenticeship schemes and traineeship providers should understand the challenges faced by young adult carers and adopt workable policies which clearly define the support and flexibility available to the young adult carers whom they employ.

## **5. What is being done locally to address this issue?**

This section will be divided into the work which is being done with adult carers and young carers

### **Support for Adult Carers in Tower Hamlets**

#### **Tower Hamlets Carers Plan**

The local Tower Hamlets Carers Plan (2015/16)<sup>37</sup> is a key local document which is setting out the forms of support which are required locally and what is being provided for adult carers. As identified throughout this document there are key areas of work which need to be addressed for adult carers and this section will identify what is being done in Tower Hamlets through the Tower Hamlets Carers Plan in relation to these issues.

- **Identification and recognition of adult carers in Tower Hamlets.**

It is recognised locally that more needs to be done to identify and work with unpaid carers in the borough. This could be achieved through a range of organisations in Tower Hamlets including the social care system, health services, housing and other local organisations. General practice are in the position to routinely collect this information and currently the NHS Health Checks provided for the 40 -74yrs population is being used as an opportunity to ask this questions and recording the response on their medical records. The results for 2015/16 NHS Health Checks delivered in Tower Hamlets showed that 72% (8662) of attendees had their carers status recorded and of these 6.3% (548) reported to being a carer. The Tower Hamlets Clinical Commission Group (CCG) through an integrated care programme are identifying carers and recognising their key role when planning care for the person being cared for. This is mirrored in the local programmes to transform the health services who have a carers stakeholder meeting to influence the changes.

<sup>34</sup> <https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf>

<sup>35</sup> [www.towerhamlets.gov.uk/.../JSNA/Lastyearsoflife\\_JSNA\\_2015\\_allparts.pdf](http://www.towerhamlets.gov.uk/.../JSNA/Lastyearsoflife_JSNA_2015_allparts.pdf)

<sup>36</sup> [https://www.carers.org/sites/default/files/young\\_adult\\_carers\\_and\\_employmentlo\\_final\\_2.pdf](https://www.carers.org/sites/default/files/young_adult_carers_and_employmentlo_final_2.pdf)

<sup>37</sup> [http://www.towerhamlets.gov.uk/ignl/health\\_social\\_care/carers/adult\\_carers.aspx](http://www.towerhamlets.gov.uk/ignl/health_social_care/carers/adult_carers.aspx)



- **Providing information and advice**

To ensure carers can access the most up to date information about services to support their role has been identified as a fundamental issue . In Tower Hamlets the council website is in the process of being updated and Local Link<sup>38</sup> has been commissioned by the local authority to provide face to face advice with carers in venues across the borough. There are a range of the services in Tower Hamlets specifically for carers from including the local Carers Centre<sup>39</sup> support networks, training sessions for carers of people with dementia and other mental health issues, a range of activities and outings to learning how to maximising their benefits and rights.

- **Prevention and early intervention**

Evidence has shown that the earlier an unpaid carer can be identified the quicker they can be offered supportive intervention to enable them to remain healthy and to maintain a life alongside their caring role. In Tower Hamlets a range of commissioned services have been made available with the aim of supporting carers to remain well. Some of these activities include:

- Short breaks/ respite care –home based replacement care is on offer for those needing a break from their caring role. Respite care is offered through the Hotel in the Park for adults with learning disabilities. Actions are taking place to improve the availability of replacement/respice care and improve the system used to book this.
- Shared lives replacement care –which enables someone to access replacement care in the community. This is currently being planned and will deliver a flexible approach for carers which will include providing short breaks, day time support, activities, intermediate and rehabilitative support. This is currently focusing on those caring for people with learning disabilities but there are plans to extend this model to other carers.

- **Carers Assessments**

Tower Hamlets council is responsible for assessing a carer's need for support however it recognised that not all carers will require a full carer's assessment. Currently in Tower Hamlets the Carers Centre<sup>40</sup> is seen as the first step in completion of the formal carers assessment, where decisions are taken if a local carer needs referral to a social worker for a full assessment. Some carers who reach the national eligibility threshold will be able to obtain a personal budget and they can access the local e-market place on the Tower Hamlet web site to identify the support options open to them. It is important that the eligible carers are accessing this funding as financial difficulties are another key issue for some carers. The Tower Hamlets Carers Centre have reported 357 initial assessments having taken place in 2015/16 and Tower Hamlet council confirmed that for 2015/16, 192 had been conducted with 98 having come from the carers centre.

Currently council officers have been working with the carers forum to improve the carer assessment form to enable easier completion. There is the need local practitioners to recognise that the assessment process provides the opportunity to understand and support carers to manage their own needs in relation to their caring responsibility and to support them to recognise the impact this role is having on their life. Recognising the needs of carers has now been incorporated into the training for local practitioners.

- **Cared for assessments and support plans**

Another important theme highlighted for carers is to be fully engaged in the assessment for the person being cared for and their expertise is listened to by social and health care professionals when planning care. 67% of local carers in the Tower Hamlets Carer Survey reported that they involved in this process however it recognised that this should be a lot higher. The Tower Hamlets practice framework used by social care is step towards engaging carers in the assessment and the integrated care programme being delivered in the health sector across the borough is aiming to include carers in the care planning process.

<sup>38</sup> [http://www.towerhamlets.gov.uk/ignl/health\\_social\\_care/help\\_for\\_adults/information\\_advice\\_advocacy.aspx](http://www.towerhamlets.gov.uk/ignl/health_social_care/help_for_adults/information_advice_advocacy.aspx)

<sup>39</sup> [http://www.towerhamlets.gov.uk/ignl/health\\_social\\_care/carers/adult\\_carers.aspx](http://www.towerhamlets.gov.uk/ignl/health_social_care/carers/adult_carers.aspx)

<sup>40</sup> <http://www.carerscentretowerhamlets.org.uk/>

### Tower Hamlets Carers Centre

The Carers Centre is a key organisation which provides independent advocacy<sup>41</sup> and rights for carers as well as providing vital links with other carers through support groups and a range of sessions to provide short breaks from the caring role. Statistics from the carers centre (May 2016) highlighted that they had 1219 carers on their register. A vast majority of the carers attending this centre delivering more than 20hours of care as indicated in Tables 13/14 where it has been recorded on 950 carers on the data base.

**Table 13 Numbers and percentages of carers providing 20-49 hours of care attending the carers centre**

20-49 hours unpaid care													
	All ages	25-34	%	35-44	%	45-54	%	55-64	%	65-84	%	85+	%
All Persons	158	25	15.8	38	24.1	37	23.4	36	22.8	19	12.0	3	1.9
Female	111	16	14.4	29	26.1	27	24.3	24	21.6	13	11.7	2	14.4
Male	47	9	19.1	9	19.1	10	21.3	12	25.5	6	12.8	1	2.1

Source : Carers Centre data base May 2016

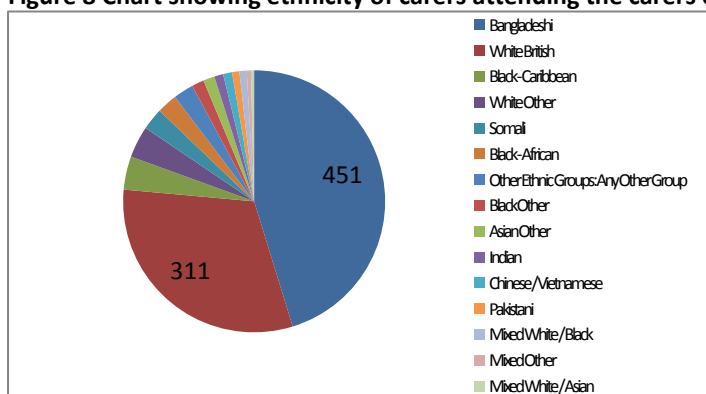
**Table 14 Numbers and percentages of carers providing 50 hrs and over of care attending the carers centre**

50+ hours unpaid care													
	All ages	25-34	%	35-44	%	45-54	%	55-64	%	65-84	%	85+	%
All Persons	792	78	9.8	166	21.0	232	29.3	172	21.7	132	21.0	12	21.0
Female	555	52	9.4	113	20.4	168	30.3	124	22.3	90	16.2	8	1.4
Male	237	26	11.0	53	22.4	64	27.0	48	20.3	42	17.7	4	1.7

Source : Carers Centre data base May 2016

Over twice as many female carers attend the centre compared to male carers (798, 330 respectively) and a large proportion of these carers (83%) whose care hours are recorded on the data base are providing 50 or more hours of care. Carers aged 45-54 yrs are the largest age group providing the highest levels of care. The census statistics highlighted that in Tower Hamlets 57% of carers providing 50hrs or more of care was found in the 35 – 64 age group. Of those attending the Carers Centre those providing 50hrs or more of care, 71% were from the same age group.

**Figure 8 Chart showing ethnicity of carers attending the carers centre where record**



Source : Carers Centre data base May 2016

Figure 8 demonstrates that 29% of the carers with a Bangladeshi background attend the carers centre and 25% with a White British background attend. The statistics provided by the 2011 census highlighted that 42% of unpaid carers are from a Bangladeshi population in Tower Hamlets and 25% from a White British background.

Of those attend attending the Carers Centre and were recorded on the data base 168 (13%) people were employed of which 86 worked part time and a further 139 were receiving a pension.

<sup>41</sup> [https://gallery.mailchimp.com/9f9b1e8977148a24ecd4d60ab/files/13\\_107\\_Independent\\_Advocacy\\_Info\\_sheet\\_v2Final.pdf](https://gallery.mailchimp.com/9f9b1e8977148a24ecd4d60ab/files/13_107_Independent_Advocacy_Info_sheet_v2Final.pdf)

**Table 15 Highest levels of conditions reported by carers attending the carers centre in Tower Hamlets**

Condition	18-24	25-34	35-44	45-54	55-64	65-84	85+	Total	% of all carers
Arthritis			4	10	53	50	3	55	4.5
asthma	2	5	7	16	8	4		42	3.4
Depression	1	8	19	33	14	7	1	84	6.9
Diabetes	4	19	35	32	32	3		125	10.3
Heart condition		2	2	6	8	8	2	28	2.3
High blood pressure		1	9	25	17	12	2	66	5.4
Spinal condition		3	21	21	16	7	1	69	5.7
Stress	16	71	89	88	65	34	3	366	30.0
Tired sleeping poorly	1	7	6	12	9	2	1	38	3.1

Source : Carers Centre data base May 2016

As previously highlighted there are high levels of ill health reported by carers particularly those who are providing longer hours of care and the Tower Hamlets Carers Centre confirms this with a wide range of ill health being reported by all carers on the data base. Table 15 highlights the most common conditions being experience by the carers attending the carers centre with high levels of stress being reported.

**Table 16 The most frequently cited reasons for caring given by carers**

Reasons for caring	Numbers	Reasons for caring	Numbers
<b>Physical Total</b>	<b>991</b>	<b>Mental Health Total</b>	<b>625</b>
Arthritis	121	Dementia	131
Mobility problems	93	Alzheimer's	75
Spinal condition	43	Depression	131
Heart condition	118	Schizophrenia	176
Diabetes	106	Bi Polar	40
Stroke	98		
Cancer	64		

Source : Carers Centre data base May 2016

Table 16 is taken from the carer's centre data set and highlights the most frequently mentioned reasons for providing care for the carers attending the Carers Centre. Of the 1616 being cared for 61% (991) have been identified as having a physical condition of which 39% (386) were due to long-term conditions. Of the mental health conditions cited 32% (206) had a recording of dementia/Alzheimer's, 28% (176) had schizophrenia and 21% (131) had depression.

### **Access to employment**

Access to employment has been shown to be a serious problem for carers both during the period of caring which can last for a number of years and following the end of that role. Carers gain a range of skills during their period caring which could be utilised in the work place. Tower Hamlets council has recently developed an initiative which supports women who have been out of paid employment for some time to receive the minimum wage whilst undergoing placements to help them achieve work experience and gain a diploma qualification in health and social care.

### **Rethink Mental Illness Tower Hamlets Carers Support Service<sup>42</sup>**

This local service provides information and support to families and friends caring for someone affected by mental illness. The voluntary sector organisation can offer individual face to face support to help resolve specific problems, opportunities to meet with other carers locally, respite opportunities, advocacy support and provide a Care and Caring modular training to provide specific support to carers supporting someone with a mental illness. The organisation accepts self-referrals and encourages referrals from primary care and the statutory mental health services.

### **Support for Young Carers in Tower Hamlets**

There is are two multiagency working groups in Tower Hamlets which consider young carers; one preparing for adulthood and the other the young people strategic group who are oversee the implementation of the Tower Hamlets Young Carers MOU. As highlight previous in this document it is vital that young carers are given right support to ensure they can reach their full potential within the education system and to carry out their caring role. Tower Hamlets council have recently commissioned, Family Actions a third sector organisation, to develop a Young Carers Support service to work effectively with schools and commissioners to improve outcomes for young carers in the education

<sup>42</sup> Email contact : [towerhamlets carers@rethink.org](mailto:towerhamlets carers@rethink.org) or [www.rethink.org](http://www.rethink.org)

system. They have been commissioned to work with 4 schools a year to provide support to identify the young carers in the schools system (many may not be recognising themselves as carers) and to embed the principles of supporting the young carers.

A young carers project which has been organised for the past 7 years in Tower Hamlets by the councils youth service runs two young carers groups per week; one for the 8 – 13yrs and the other for the 13 -18yrs where they provide a range of support offering a 'safe space' for young carers to engage in fun, learning and social activities which provides a break from their normal caring responsibilities. All learning has a practical life skill element to the development and awareness of their knowledge around safeguarding such as gas and electricity safety in the home

### **Better Care Funding**

Twenty two schemes are supported in Tower Hamlets under this funding stream which provides an opportunity to transform care so that people are provided with better integrated care and support. The schemes have been developed collaboratively in order to make a positive impact on those who are being cared for and on their carers. The BCF programme can be summarised as follows;

- Integrated care – improving the coordination of care between hospital, social and general practice care, including 7-day working for hospital social work
- Improving mental health care provision including dementia and autism services and providing support to carers of service users
- Schemes to provide for and assist carers to care more effectively and safely both for themselves and the person they are caring for.
- Supporting those with disabilities to remain independent and live in their own homes.
- Enhanced support for carers, including care packages, the provision of a Carers Centre and ensuring the necessary infrastructures are in place for information, advocacy and guidance.

## **6. What evidence is there that we are making a difference?**

Currently there is no background evidence locally produced which to indicate if a difference is being made or the impact of local services, apart from the Carers Survey. However the Carers Survey does not use consistent questions which adds to the difficulty of measuring differences over time.

## **7. Impact on Public Health Outcome Framework indicators**

### **Public Health Outcomes Framework:**

Domain 1 Improving the wider determinant of health:

1.3 Pupil absence

1.5 16 – 18yrs not in education or employment

1.17 Fuel poverty

1.18 Social isolation

Domain 2 Health Improvement:

2.11 Diet

2.12 Excessive weight

2.14 Smoking prevalence

2.20 access to cancer screening

2.21 access to non-cancer screening

2.23 self -reported well being

Domain 4 – Preventing premature mortality.

### **Adult Social Care Outcomes Framework (ASCOF)**

Domain 1 – Enhancing quality of life

Domain 3 – Positive experience of care and support

### **NHS Outcome Framework (NHSOF)**

Domain 2 – Enhancing quality of life for people living with long-term conditions

Domain 4 – Ensuring that people have a positive experience of care

## **8. What is the perspective of the public on the support available to them?**

In Tower Hamlets, funding from the Community Intelligence Bursary made available in 2015 to local 3<sup>rd</sup> sector organisations to obtain the views of local residents from a range of priority groups which included carers. Over 90 local informal carers were interviewed by three 3<sup>rd</sup> sector organisations based in Tower Hamlets. A large number of the participants were not aware if they were entitled to any statutory support or where to find other forms of support in the community. This was often due to isolation and the need for language support which was particularly mentioned by carers from the Somali community. They reported that they would benefit from learning about health for themselves and the people they cared for particularly in relation to manual handling and first aid.

Information from the Tower Hamlets Carers Survey (2014) found that 46% of respondents said it was easy to access information (nationally 49%). However 31% reported that it was difficult to access information compared to 23% nationally and further 23% of the carers from this survey reported they had not tried to access information.

When asked in the survey “do you feel that the care you and the person you care for receive is co-ordinated well?” 47% of respondents in Tower Hamlets agreed and 17% disagreed. Carers who have had an assessment from the Carer Centre in Tower Hamlets were more likely to report a positive experience (50% compared with 42% who had an assessment from a Council practitioner). Asian respondents were significantly more positive on this issue than White respondents: 56% of Asian respondents agreed that care is coordinated well compared with 39% of White respondents. There was an age difference with the response with those aged 18 – 44 yrs being more positive than those in older age groups

From a previous carer survey (2013) carers in Tower Hamlets report feeling less supported by services than average. Only 76% of carers in Tower Hamlets report feeling ‘always or usually’ supported by their GP, compared to 81% nationally. 75% of carers in Tower Hamlets report feeling ‘always or usually’ involved in hospital discussions about the person they care for, compared to 82% nationally.

In January 2015 the Tower Hamlets Carers Centre provided comments on some of the current issues being experienced which confirmed many of the issues mentioned above but also included:

- the current social and economic climate are having a detrimental impact on their lives as carers in Tower Hamlets
- the difficulties of getting hold of social care staff
- feeling that the Care Act is raising hopes that cannot be fulfilled as there is no more money
- the difficulties of overcrowding and the lack of access to local social housing

There have been growing concerns about the improvements required to the carers assessment. Carers have reported that self-assessment forms have been sent into the council and it has taken many months to receive a reply. Council officers have been consulting with the carers forum to improve the documentation for the assessment and although the recommendations carers are reporting their concerns about the slow progress on this issue.

## 9. What more do we need to know?

### Adults Carers:

- We need to know if front line health and social care services are becoming more systematic in identifying carers within their systems.
- We need to know what improvements are required to enable local carers to be more involved in the health and social care decisions made on those they are caring for.
- We need to know more about those who are not accessing services, to know what level of support may be required in the future to enable them to continue their role. Currently there is a large gap between the numbers of carers on the census date and the level of carers known to services.
- We need to know the more about the health status of local carers including the numbers with long-term conditions and -life-style measures.
- We need to know if the support services are reaching all the most vulnerable carers in Tower Hamlets particularly those delivering over 50- hours of care a week.
- We need to know more about the changing needs of carers, when support interventions would be more effective and more information on needs of carers from different ethnic groups
- We need to know what are the outcomes and future needs for adult carers are following a bereavement of the person they have been caring for particularly if this has been over a long period of time
- We need to know how well the carers are equipped to deal with the health conditions and well-being of the person/s they are supporting to prevent the exacerbations of their conditions.

### Young Carers

- We need to know who the young carers are as currently there is an under representation of young carers known by services in Tower Hamlets compared to the numbers of young carers on the census data.
- We need to identify all the young carers still at school and to identify their needs to provide appropriate support.
- We need know if all local young carers are achieving the same potential as their peers through the education system and during transition in Tower Hamlets.
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## 10. What are the priorities for improvement over the next 5 years?

Following consultations it is recognised the most important priority is the identification of carers in Tower Hamlets particularly those who are providing over 50 hours of care per week. Therefore the first section of the following considerations, which are based the National Carers Strategy, are the key priorities for Tower Hamlets i.e. the identification of carers. The Tower Hamlets Carers Strategy (2016-19) is currently being produced which will provide the key priorities for the borough together with a detailed plan demonstrating how this will be implemented in the future.

Current state	Evidence for effective intervention	Considerations
There Carers Strategy is being developed and work being organised in both health and social care services which is addressing some of the need of carers in Tower Hamlets.	National carers strategy priorities	To organise a multi-agency meeting in Tower Hamlets to develop and oversee the implementation of the carers strategy to take the recommendations in the future action plan forward.
<b>Identification and recognition of carers</b>		
Currently there is very little publicity and awareness raising on carers and their essential roles in Tower Hamlets.	To improve the identification of carers within the community by statutory and voluntary sector organisations through awareness raising initiatives on carers and roles.	To increase the visibility of carers and their roles within the community to facilitate an improvement in the identification of carers in Tower Hamlets. To raise awareness amongst local people in Tower Hamlets to help them to recognise if they are a carer.

<p>There is a large gap between the numbers of adult carers on the census and those known to services.</p> <p>Currently general practices are identifying carers through the NHS Health Check.</p> <p>There is not consistent identification and recording of carers in social care interactions.</p>	<p>To identify adult carers in a local area is a key recommendation of Carer's Strategy. Given the reported low level of health and quality of life among this group, this is a critical first step in improving access for those who would benefit from it.</p>	<p>To encourage front line health and social care staff to ask people if they are carers, the hours they are providing and recording this information. To offer appropriate support information as required.</p> <p>To continue to identify opportunities for the recording of carers to take place in primary care.</p> <p>To work towards developing improved communication between health and social care on carers identified.</p>
<p>There is a large gap between the number of young carers identified on the census and those known to services</p>	<p>To identify young carers in a local area is a key recommendation of the Carers Strategy. Local young carers report a gap in access to support.</p>	<p>To recognise the opportunities for schools, health and social care to identify young carers.</p> <p>To improve the referrals to an IPST assessment for newly identified young carers.</p> <p>To develop the IPST assessment to collect information to demonstrate the progress of a young carer eg educational attainments.</p>
<p>In Tower Hamlets 75 % of adult carer reported that they are being recognised for their role when planning health or social care for the person cared for.</p> <p>Carer representatives are currently contributing to the Carers Strategy in Tower Hamlets</p>	<p>National recommendation that health and social care professionals involve carers throughout the process of planning and supporting a person who is cared for.</p>	<p>To identify the opportunities to increase the involvement of carers in all health and social care planning in both health and social care services.</p> <p>To continue to enable the voice of carers to be heard and to influence future health and social care action plans as a result of the strategic developments</p>
<p>Tower Hamlets CCG integrated care programme which is bringing together health and social care to plan care for people with serious long-term conditions.</p>		<p>To work towards recognising the roles of carers in the integrated care planning process and to acknowledge carers as equal partners, to health and social care staff in the care plans.</p>
<p>Currently unable to access information on recording of carers in health systems. There is no clear health offer for carers triggered by the identification within health services.</p>	<p>Nationally it has been recognised that carers need support to improve their skills in delivering care to those with long-term conditions.</p>	<p>To provide specific training programmes for carers or use other training opportunities to support carers to develop new skills to improve the care given to those with long-term conditions. This could be important in support the unplanned admissions agenda.</p>
<p><b>Realising and releasing potential</b></p>		
<p>Currently there is a programme running in 4 local schools to identify and support young carers in the education system and there are two local groups being organised on a weekly basis to support young carer known to services by the youth team.</p>	<p>Evidence shows that providing appropriate support to young carers in the education system is key to trying to ensure that they reach their optimum potential in the education system and obtain employment opportunities</p>	<p>Using the learning from the local school programme to decide on the next steps with schools in Tower Hamlet to support young carers through the education process.</p> <p>To identify ways of assessing the young carers progress through the education system.</p>
<p>In Tower Hamlets an employment programme has started to enable women to return into employment. It recognises the multi-skills of carers and</p>	<p>National evidence indicates that carers skills are not fully being recognised when trying to enter the employment market. Employers are often not recognising the</p>	<p>To identify ways of expanding the current employment programme if it has successful outcomes.</p> <p>To work with local employers who</p>

provides a recognised qualification to enter into social and health care employment.	needs of their employees who have a caring role.	employ local residents, to recognise the flexible working options which could be available to employees, with caring responsibilities, to prevent them leaving employment.
It is locally recognised transitioning from parent to carer (ie from looking after a child with special needs who is becoming an adult) or a young carer who is transitioning into adulthood, are key times when more support could be required.	Evidence from young carer's research highlights the vulnerability of young carers at a time of transitioning into adulthood.	To ensure that the experience of transition is recognised in the local carers strategy and through engagement with carers identifying ways to support and manage this process in the future.
<b>A Life alongside caring</b>		
<p>Access to information and advice for carers is on the Tower Hamlet LA web site with a wide range of support services as well as information on health and wellbeing services which can be accessed locally.</p> <p>Opportunities for face to face support can be found through a range of organisations in Tower Hamlets including the Carers centre, Link Age plus, and the Alzheimer's Society .</p> <p>Despite the numbers of services on offer local carers have reported they do not know what is available and this has been is a particularly issue for those from the Somali community.</p>	Information and advice is important for carers to get the appropriate support to maintain their health, wellbeing and independence to enable them continue their caring role.	<p>To ensure that Carers needs are considered in the delivery of information/advice systems in health care using vanguard funding.</p> <p>To ensure all the organisations offering advice and advocacy to carers are kept fully informed of the developments.</p> <p>To develop information which is accessible to communities who do not have English as their first language.</p> <p>To monitor the numbers of carers accessing the local TH web site and local face to face services.</p> <p>To develop an inclusive strategy to publicise all services to carer throughout the borough.</p>
Respite care and carers breaks are offered in Tower Hamlets for a limited number of carers who require this support particularly those who are looking after people with learning disabilities or dementia.	Evidence shows that for carers who are particularly spending long periods of time caring they need breaks from this role particularly for their own wellbeing and mental resilience.	Tower Hamlets council is currently undertaking a review of services being offered including versatile ways of giving breaks to carers.
<b>Supporting carers to remain healthy</b>		
The census highlights the number of carers providing over 50 hours of care however in Tower Hamlets we are not aware of how many of this group of carers are accessing local services or of their health status.	Evidence indicates that the more hours of care provided the more likely it is to lead to poorer long-term health outcomes for the carer	<p>To start to identify the carers who are providing 50hrs + of care through primary and social care with a view to identify the needs of this particular vulnerable group to manage their health and well-being outcomes.</p> <p>To identify how health checks for this group of carers could be developed in primary care to improve or maintain the carer's future health outcomes.</p>
<p>A range of health promoting activities commissioned in Tower Hamlets however there is no information of how accessible these are to carers living in the borough.</p> <p>There are no current statistics in Tower Hamlets to identify if carers are attending the range of national health screening programmes which are targeting sections of the local population.</p>	Evidence shows that carers, similar to other groups in the population would benefit from specific health promoting activities and to attend health screening programmes which are provided in the borough to diagnose disease at an early stage.	For Public Health to take into account the access and needs of local carers when developing local health promoting activities, to challenge the health inequalities being experienced. Increasing at the identification of carers in primary care will demonstrate if this cohort is accessing all the available screening programmes.



There are a range of long-term conditions care pathways in general practices in Tower Hamlets for people with diagnosed conditions. It is not known how many carers have long-term conditions but it is known that many carers do not have the time to take care of their health.	NICE guidelines for a variety of long-term conditions recommends that these are managed in a systematic way in general practices to prevent further complications.	To investigate how many local carers have a long-term condition and if they are managing to attend appointments to manage their disease and prevent the onset of complications.
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## 11 Key contacts /stakeholder involvement / links to further information

Tower Hamlets Carers Centre: <http://www.carerscentretowerhamlets.org.uk/> 020 7790 1765  
 Tower Hamlets CCG  
 East London Foundation Trust  
 Tower Hamlets Local Authority : Adult Commissioning / Adult Social Care / Strategic-Policy-Performance / Corporate Research Team / Children's Services

## 12 Communication strategy/plan

Tower Hamlets Carers Strategy (2016/19) is being developed and used the background evidence from this JSNA. An action plan is to be produced and will form the basis of the work with carers over the next 3 years.

## 13 Crosscutting links with other JSNA topics

There are links with a wide range of JSNAs, including (but not exclusively):  
 Older People's JSNA  
 End of Life JSNA  
 Mental Wellbeing JSNA

### Factsheet info

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### Factsheet signoff

<b>Date signed off by Senior JSNA leads</b>	<b>Signed off by (Public Health Lead (name) )</b>	Flora Ogilvie 25 <sup>th</sup> October 2016	<b>Date signed off by Strategic Group:</b>	<b>Sign off by Strategic Group (name):</b>	
	<b>Signed off by (LBTH Lead if different to above(name)):</b>				