

London Borough Of Tower Hamlets

**Tower Hamlets
Carers' Strategy
2016/19**

This strategy acknowledges the huge amount of work undertaken by carers in Tower Hamlets. Through recent involvement and engagement activity they have given us a better understanding of their caring role and we, in turn, recognise the high value of the support they provide. carers offer incredible support to the people they care for and for that we thank them.

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Welcome to the Carers' Strategy for Tower Hamlets

Foreword

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Introduction

Why we need a Carers' Strategy

Many of us at some point in our lives will care for a relative, friend or neighbour who needs support in their daily lives. Carers come from all backgrounds and can be of any age. They may be working or in education. They may also have support needs themselves, or, in the case of young carers, the extent of their caring role may be inappropriate. There are nearly seven million carers in the UK and this number is expected to rise as people live longer. It is anticipated that by 2037 the number of carers in the UK will increase to 9 million¹. Carers play a vital role in providing unpaid support to children and adults who are frail, ill, disabled, or who have mental health or substance misuse problems. This can at times affect Carers' own health and wellbeing. Latest calculations of the value of unpaid care in the UK show that the contribution of the UK's carers is growing and is now worth £132 billion² nationally per year. The government has recognised the importance of supporting carers of all ages through the 2014/16 National Carers' Strategy, 'Recognised, Valued and Supported, the next steps for the Carers' Strategy'; the Children and Families Act 2014, and the Care Act 2014 which, for the first time, placed the needs of carers on a par with those they care for.

The 2011 census identified 19,356 residents in Tower Hamlets who provide some form of unpaid care. 3,326 of these are young carers and young adult carers under the age of 25. Many young carers remain hidden from view, due to the fact that they are less likely to ask for support in their own right or concerns that their parents may have about asking for support. In 2010, the BBC conducted a survey of 4,000 school pupils. This found that one in twelve undertook moderate to high levels of caring responsibility. It was estimated that there are approximately 700,000 young carers. This is substantially higher than the 166,000 that have been identified in the last census. As a result of this survey, it is likely that the number of young people caring in Tower Hamlets is much higher than previously thought.

The data we have suggests that carers in Tower Hamlets represent 7.6 % of the population. This is lower than the London and England averages, which are both 8.4%. However, when compared to London and England averages, Tower Hamlets has a higher proportion of residents providing more hours of caring support per week: 18.1% provide 20-49 hours of care per week, and 25.4 % provide more than 50 hours of care.

¹ Carers UK, 'Facts about Carers', October 2015

² Carers UK, the University of Sheffield and the University of Leeds (2015) Valuing Carers 2015 – the rising value of Carers' support, S. Yeandle, L. Buckner

The Care Act 2014, the Children and Families Act 2014 and the National Carers' Strategy³ mark a significant shift in the approach to how carers are supported, acknowledging the important contribution they make and placing them on the same legal footing as the person they care for when it comes to accessing services they may need.

Each Carer's experience is unique to his or her own circumstances and the care and support they provide can vary. However, carers share many similar experiences and challenge that impact on different aspects of their lives: for example, looking after their own health, having a life of their own and doing things they enjoy, coping financially, juggling caring roles with education or paid employment, and managing multiple caring roles or other family responsibilities.

This strategy has been written in response to the needs of the 19,000 plus carers who live in Tower Hamlets and the requirements of the National Carers' Strategy, the implementation of the Care Act 2014 and Children and Families Act 2014.

It has also been produced as a direct response to a health scrutiny challenge session, held on 13th May 2015 at Tower Hamlets Carers' Centre. The challenge session focused on how the Care Act 2014 had been implemented locally, specifically in relation to the council's duty to unpaid carers. It was attended by a range of stakeholders including councillors, officers from adult social care services, providers of Carers' support services and local carers. The discussions focused on how we can improve services for carers to enable them to continue with their caring role and improve their health and wellbeing. A key recommendation made was "that the Carers' Strategy be developed in partnership with local Carer service providers, the Carers' Forum and in consultation with local carers". Key recommendations from the health scrutiny challenge session have been embedded into this strategy.

This strategy presents what we know about caring in Tower Hamlets, based on the views and needs of carers themselves and describes the changes we'd like to see over the next three years to meet these needs. With growing recognition of the value that carers bring to our health and care systems, and an increased focus on the wellbeing and life chances of carers of all ages, it sets the framework for an outcomes-based approach to recognising, respecting, working with and supporting carers. It includes an outline of national and local priorities for carers, addresses our statutory responsibilities, considers how we are currently meeting the Carers' needs of, and describes a set of principles which will shape how we work together in partnership to achieve improved outcomes for carers in Tower Hamlets.

This strategy has been developed in the spirit of co-production through extensive engagement and involvement with carers based at the Tower Hamlets Carers' Centre and Sonali Gardens Day Centre. These include

³ Recognised, Valued and Supported, the next steps for the Carers Strategy & Carers Strategy: Second National Action Plan 2014–2016

carers of people with physical disabilities, learning disabilities and mental health issues. We have also collected feedback from individuals, such as those who care for somebody with a substance misuse issue, who also wanted to share their views with us. Their real life experiences have shaped the content of the strategy and helped us to recognise the challenges and rewards that come with being a Carer.

Young carers who attend the Tower Hamlets Young Carers' Project were also consulted with and their views sought. This engagement helped to ensure that the voice of young carers is reflected throughout the strategy,

We recognise that working with small groups can never fully represent every view or experience, but we hope that the insights provided ensure that this document captures the key issues faced by most carers.

Legislative Framework

The Care Act 2014 enshrines the need to consider both the needs of the cared-for person and the Carer. It recognises the value of the support that carers provide to their loved ones and the need to ensure that their health and wellbeing is looked after.

The Care Act places a responsibility on local authorities to identify carers with unmet needs within the local population and to make provision. This may involve undertaking formal Carer's Assessments.

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.

It adopts a whole-family approach as well as more personalised support, tailored to the Carer and the person they support, using new national eligibility criteria. Carers are now recognised in law as having the same legal right to an assessment and support as the person they care for. They no longer have to demonstrate that they provide 'regular and substantial' care to have a Carer's assessment. The assessment must consider whether the Carer is able or willing to carry on caring, their own needs, the impact caring has on their lives and what they want to achieve, such as working, studying or doing more socially. The local authority then has a duty to agree a support plan with the Carer, which sets out how Carers' eligible support needs will be met.

The Act requires local authorities to provide, or arrange the provision of services, which will prevent or delay the need for care and support by unpaid carers as well as the person they care for, in order to reduce the need for support by carers in their area. In addition or instead of direct provision, local authorities should consider whether it is in a person's best interests that they be signposted, directed or referred to independent sources of information and advice. Local authorities must establish and maintain a service for the

provision of information and advice about care services and how to access them, including financial advice.

The two most significant pieces of legislation in respect to young carers and the responsibilities that the local authority and others have towards them can be found within the Care Act 2014 and the Children and Families Act 2014.

The Children and Families Act 2014 states that any young person under the age of 18 has a right to an assessment regardless of who they are caring for the type of care or how often they are providing it. This assessment should be carried out based on the “appearance of need”, meaning that a young person no longer has to make a request for an assessment nor do they have to be carrying out “regular and substantial” amounts of care. A young person still has the right to request that a Carer’s Assessment is undertaken.⁴

The assessment must look at the care that the young person is providing but also the care that they intend to provide in the future. The assessment must take into consideration the views of the young person and their wishes and aspirations for the future. The local authority must consider whether it is appropriate for the young person to be undertaking the caring duties and if a service could, or should, be provided to the person being cared for.

The assessment must also have regard to the education, employment, training and recreation needs of the young person and establish whether the caring needs will have a detrimental impact on these. It must also identify whether it will impact on the young person’s emotional, physical or mental health.

The Care Act 2014 also places a responsibility on the local authority to assess the needs of a young Carer, where it is felt that they may have needs after turning 18. This assessment should look at the needs of the young carer in preparation for them becoming an adult.

Our vision

This strategy is a key document and will be used by Tower Hamlets Council and Tower Hamlets Clinical Commissioning Group (CCG) to understand how best to work with and support local carers. It will also support us to define priorities and responsibilities for the future, identify potential gaps in services and illustrate how we will work towards improving them. It will enable us to coordinate the wide range of partner organisations required to achieve these priorities.

Our vision for this strategy is based on the National Carers’ Strategy:

Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their

⁴ Children and Families Act 2014, s96

caring responsibilities and a life outside of caring, while enabling the person they support to be a full and equal citizen.

This vision has been developed with, and agreed by, a group of local carers, through Tower Hamlets Carers' Strategy Group. This vision illustrates our commitment to carers going forward.

Our aims and priorities

This strategy aims to ensure that carers are respected, that they have access to good quality information, that they access the services and support they need to care for their relative or friend and that they have a life of their own. Together with service users from the carers Centre, we have developed a shared understanding of our key aims for the Partnership. These are broadly aligned to the National Carers' Strategy;

1. Identification and recognition:

Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages

2. Realising and releasing potential:

Enabling those with caring responsibilities to fulfil their educational and employment potential

3. A life outside of caring:

Personalised support both for carers and those they support, enabling them to have a family and community life

4. Supporting carers to stay healthy:

Supporting carers to remain mentally and physically well

5. Transitions:

Supporting young carers to make the transition to Adult Services smoothly, providing the necessary information and guidance to parents of a young person that is transitioning in to Adult Services.

Who is a Carer?

Within this strategy the term 'Carer' is taken from the Government's National Carers' Strategy:

“A Carer is someone who spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.”⁵

However, as the National Strategy acknowledges, many people find it difficult to see themselves in this role and do not always wish to be identified as a Carer as for them the caring relationship is simply part of everyday normal life as a wife, husband, partner, son, daughter, parent or friend.

This strategy sees the need for recognising both Carer and cared-for person as ‘Expert Partners of Care’ to work towards providing person-centred support. It is recognised that carers may:

- be caring for or supporting a husband or wife, mother or father, son or daughter, brother or sister, neighbour or friend, or quite often, caring for more than one person.
- be helping with food preparation, assistance with eating and drinking, shopping, laundry and cleaning or other domestic tasks, or may take this person to appointments or provide other transport, help with medication, bathing or other personal care needs, or may provide emotional support or ensure safety.
- support someone who is frail or elderly, who has learning or physical disabilities or sensory impairments, has a mental health condition or substance misuse issues, or any number of other health situations where the person requires additional support. A person cared for may not fall into the eligibility threshold for benefits or additional support for themselves, but may still be provided with a great deal of support.
- have been caring for a long time, or be a new carer, or their caring role may be ending or may have recently changed or come to an end.
- be a hidden Carer. (A hidden Carer is someone who may not be known to services as a Carer and is hard to reach for support. They may not recognise that what they do for a loved one makes them a Carer. They may also be experiencing other barriers to recognising and accessing information, advice and support.

It is important to note that within this overarching definition of a Carer, there are a number of different caring groups:

- **Adult carers** are adults caring for adults over the age of 18. This could include a spouse, parent, adult child, other relative or friend.
- **Young carers** are children or young people under the age of 18 who provide regular, ongoing care and/or emotional support to a family member or other person who is ill, disabled, living with mental health issues or misuses alcohol and/or substances. This care is over and above helping out or the usual caring for an adult or a sibling.
- **Parent carers** are parents caring for an ill or disabled child or young person under the age of 18 to a degree greater than would be expected in a parenting role. Parents will often see themselves primarily as parents but

⁵ Carers at the Heart of 21st Century Families and Communities’, Department of Health 2008

their child will have additional care needs and may be entitled to additional services.

For the purposes of this strategy, the term ‘Carer’ does not include any Carer or personal assistant who gets payment either in cash or in another way for the care they provide; or who works as a volunteer on behalf of a voluntary organisation.

Children who care for a parent who misuses substances are amongst the most difficult to identify. Often these children would not self-identify as carers and the parent would be reluctant to ask for support due to the often criminal nature of their substance use. In its 2011 report “Hidden Harm – Responding to the need of Children of Problem Drug Users”⁶ the Advisory Council on the Misuse of Drugs estimated that there were between 200,000 and 300,000 children in England and Wales where one or both of their parents had serious drug problems. Children in these situations often take on a parenting role which has a significant impact on their school attendance and attainment.

Adults who care for loved ones who have substance misuse issues are also very difficult to access for similar reasons to those stated above for young carers. These carers often do not consider themselves to be carers which make providing support difficult.

Profile of carers in Tower Hamlets

The most detailed and complete source of data concerning the number of carers comes from the national census of population, which is undertaken every 10 years. The last census took place in 2011, and while it is important to note that Tower Hamlets has a rapidly changing population, this is the most reliable data that is currently held.

In 2011, 19,356 residents in Tower Hamlets identified themselves as unpaid carers. This represented 7.6% of the population. This is slightly lower than the London and England average which are both 8.4%. We know, however, that carers in Tower Hamlets provide more hours of care than other areas. As demonstrated by the table below, 43.5% of carers provide more than 20 hours of care per week, compared to 36.9% in London and 36.4% across England.

Table 1 Provision of hours of care

	Tower Hamlets (No.)	Tower Hamlets (%)	London	England
Residents providing unpaid care	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)

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https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/120620/hidden-harm-full.pdf

According to the census, Tower Hamlets has a larger proportion of carers in the younger age groups compared to national and London data. 567 (2.9%) of carers in the borough are under 15 and a further 2,795 (14.4%) are between the ages of 16 and 24. If it is assumed that the proportion of carers is evenly distributed across the age band, then it could be suggested that there are at least 1,265 young carers in the borough.

Table 2: Age of carers, 2011

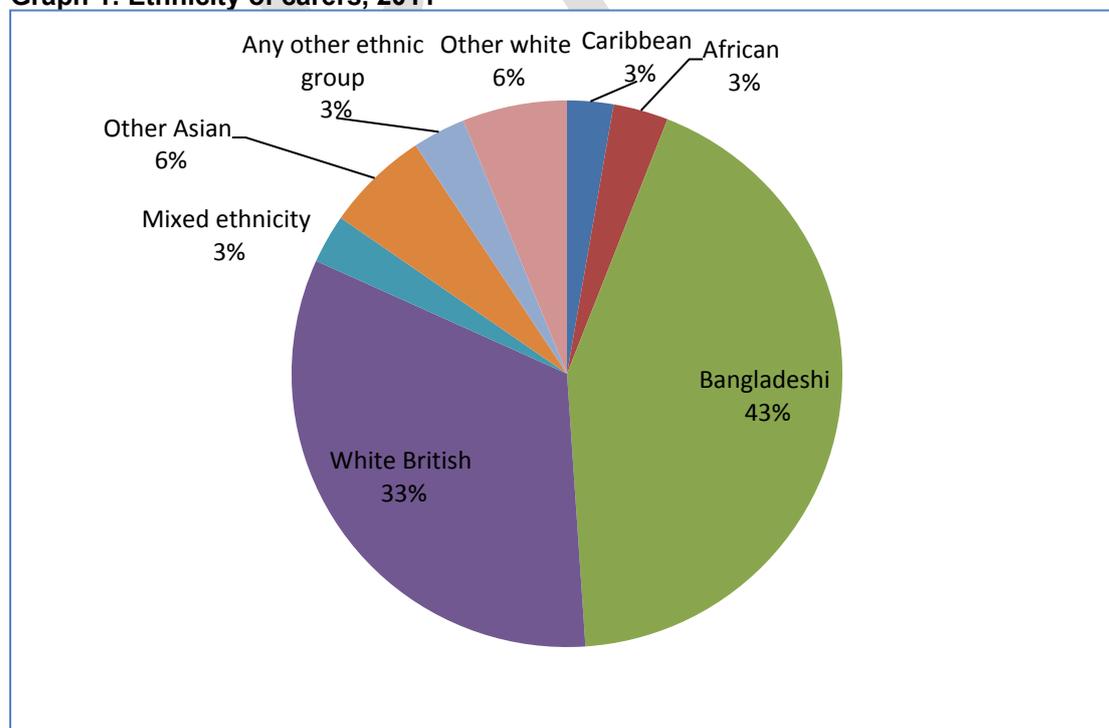
Age	Tower Hamlets		London		England	
	Number	%	Number	%	Number	%
All Ages	19,356	100	689,973	100	5,430,016	100
Age 0 to 15	567	2.9	17,381	2.5	111,423	2.1
Age 16 to 24	2,795	14.4	54,577	7.9	302,356	5.6
Age 25 to 34	4,737	24.5	93,741	13.6	473,891	8.7
Age 35 to 49	5,681	29.4	204,950	29.7	1,420,318	26.2
Age 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)

8,320 (42.9%) of all carers were identified as being from the Bangladeshi community. The next largest group is White British, which accounts for 6,357 (32.8%) of the carers in Tower Hamlets. Bangladeshi carers are also more likely to provide a larger amount of care than those from other ethnic groups.

The Bangladeshi community makes up approximately 32% of the population of the borough, so is over-represented in these statistics. This compares to an under-representation of White British carers. 45% of the population is White British compared to 32% of carers.

Graph 1: Ethnicity of carers, 2011



Source: 2011 Census

29% of Bangladeshi carers report undertaking more than 50 hours of unpaid care, compared to 25% of White British carers.

55.8% of the carers in Tower Hamlets are women, with 44.2% being men. This is slightly below the London average (57.5%) and the England average (57.8%). However, significantly more women (66%) provide more than 50 hours of care than men (34%).

Table 3: 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)

A much smaller number of young carers are currently on the Young Carers' Register which indicates that a significant number of young carers may not be receiving any additional support either from the council or other services.

What we spend on Carer Services in Tower Hamlets

In 2015/16 the Council spent £2.8 million on Adult Carer services. This included approximately £360,000 to fund Tower Hamlets Carers' Centre and roughly £501,000 to fund a range of different short breaks and respite services.

One of the main areas of support for parent carers of children with disabilities is in the area of short breaks. These are services either commissioned or delivered in-house for children with complex needs which provide essential support for the service user but also an opportunity for their carers (usually their parent) to have a break from their caring responsibilities. The budget for short breaks is currently £1.8m.

Currently we spend £93,500 on young carers. Targeted support is provided via a young Carers' support group which provides respite activities, and personal support with education or employment issues. Schools can access a dedicated project for Young carers, whereby Young Carer champions are developed and appointed within each school to ensure that the needs of their carers are identified and met. This is in addition to the pastoral care that many schools provide in conjunction with the local authority's attendance and welfare service, which aims to look after the welfare and emotional well-being of their pupils. Children's mental health support services within Adult Mental Health teams also provide a targeted additional resource.

Our Priorities

Priority 1: Identification and recognition

We will aim to support those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.

What carers have said

“I’ve been doing this for 10 years, but I didn’t know that I was a Carer”

“I’m a Carer now, not a wife. I struggle with this.”

“GPs play a key role, and greater communication is needed through local practices and health centres”

“Community groups could be doing more outreach to improve identification of carers.”

“As a Carer I have clear understanding of what works and does not work for the care of my son ... Ignoring carers is not only bad practice but it will always cost more in the long term.”

“My school didn’t know I was a young Carer; this was only recognised when it started to affect my school attendance.”

“School have a notice board and an assembly about young carers. I know where I can go if I need help”

Carers do not always identify with the term ‘Carer’ and feel that health and social care professionals do not always recognise their role in relation to the person being cared for. As a result, many carers currently miss out on the support, including emotional support and financial assistance, to which they may be entitled.

All professionals need to be more aware of carers and their specific needs; they don't seem to know about the role of a Carer or the Carers' Centre (specifically community-based teams). A number of the carers we spoke to told us that signposting to Carers' services was not routinely done, especially when dealing with their GPs.

Some carers also felt that they were made to feel as though caring was their duty.

While the Carers' Centre was good, they should be doing more to raise their own profile. Although the Carers' Centre is a much valued resource, we were told that carers do not always know about it.

Some carers felt they were not acknowledged by health and social care professionals and that they were not consulted on the care of the person they cared for.

Carers also told us that one of the major frustrations and difficulties was the feeling of being passed from one person to another, often from one agency to another. All agencies must work together to address this experience and it is likely that a training programme will be required to address this experience. Staff should understand what it means to be a Carer and the difficulties that can come with taking on such a demanding role.

What should we be doing?

Supporting people with caring responsibilities to identify themselves as carers so they can access the information, advice and support that is available

A significant number of people with caring responsibilities do not readily identify themselves as carers. They understandably see themselves primarily as a parent, spouse, son, daughter, partner, friend or neighbour. The concept of caring is assumed but not recognised in some families in ethnic minority communities. The consequences are that many carers are not offered or do not seek early access to information and advice on the specific illness or condition of the person they are supporting to help them care effectively and safely. They may also find it hard to know how to access information and advice on how to balance a caring role with other responsibilities and opportunities in their lives. Decisions about education and employment; support from the welfare and benefits system, and their own health and well-being may be overlooked. Many older carers can feel socially isolated, especially if they are looking after someone with dementia, have health problems themselves or find it difficult to access public transport.

Access to relevant and timely information and advice is also vital throughout the caring role, particularly at times of significant change - for example, to help parent carers negotiate the transition from children's services to adult health and social care services, and at the end of life when the caring role is over.

Carers feeling their knowledge and experience are valued by health and social care professionals

One of the strongest messages that came through in the involvement and engagement work with carers in the borough is the frustration that many carers feel about their experience of working with health and social care professionals. Carers often do not feel valued or recognised as an expert and equal partner in care. Carers reported that they have developed an expert knowledge of the condition of the person they are supporting and have a close understanding of that person's own aspirations and needs. This is seen as a particularly problematic issue once the person they look after is admitted into hospital and carers believe they should be involved in planning and designing hospital discharge arrangements and individual care packages, as they are key partners in ensuring effective delivery of care at home. The breakdown of hospital discharge arrangements can lead to readmissions that are both costly in terms of resources and stressful for the individual, carers and families concerned.

Involving carers in planning individual care packages and in developing local strategies that will impact on carers or the people they care for

Councils and their strategic partners should routinely involve carers in their Joint Strategic Needs Assessment and development of local Carers' strategies to ensure that the needs of carers of all ages within the local population, including carers within ethnic minority communities, are adequately reflected. It was clear from involvement and engagement work with carers in Tower Hamlets that former carers or those currently caring with the capacity to do so would like the opportunity to put their expertise to good use, particularly if it can help current carers.

Carers in Tower Hamlets have stressed that assumptions should not be made about who will provide care and to what extent. A whole family approach in assessment, enabling both the individuals who need support and those who will support them to identify their own needs and desired outcomes, is much more likely to result in individual care packages that can be sustained effectively. A whole family approach will also minimise the risk of young carers feeling forced into undertaking inappropriate caring roles and being at risk of harm. It is clear from involvement and engagement work with carers in Tower Hamlets that it is likely many carers will be supporting more than one person - i.e. inter-generational or multi-generational caring, or providing a lifetime of care, for example when supporting someone with learning disabilities. With changing family structures and more mobile communities, many families will be 'distance Carers', unable to provide regular day-to-day care although providing significant support to their relative.

What are we currently doing

It is recognised locally that more needs to be done to identify and work with carers in the borough. As noted above, the 2011 Census identified 19,356 carers in Tower Hamlets; of which 4,917 provide fifty or more hours of care

per week. However in 2015/16 only 1,407 adult Carers' accessed support services for carers in Tower Hamlets.

General Practices are likely to be the first point of contact for somebody who is struggling to cope with their caring role and presenting physical and emotional symptoms associated with this, such as stress and anxiety. GPs are therefore in an ideal position routinely to identify and signpost carers to support services in the borough. However, latest available data reveals that this isn't happening as much as it should. There are 304,034 people registered on the GP database in Tower Hamlets. Of these, only 40,864 have had their Carer status recorded, which shows that the GP has checked if they have any caring responsibilities. Only 3,242 people out of the 40,864 asked have been flagged as a Carer by their GP. Similarly, data from NHS health checks in Tower Hamlets provided for people aged between 40 and 74 years old reveals that of the 12,053 who received a health check in 2015/16, only 8,662 (72%) were asked if they were a Carer. Of those asked whether they had any caring responsibilities only 548 (6.3%) were identified as a Carer.

Currently, the Council encourages adult social care staff and staff in provider organisations to identify and support all carers, including carers who do not live in the borough but care for someone who does. Our new Practice Framework adopts a whole family approach to the assessment of needs, encouraging greater identification of carers and the wider support networks around vulnerable individuals. This means that all carers who may need support are able to get it at an early stage. It also means we have a holistic view of the care being provided to a person. (For example, a service user may have a Carer living far away who is still able to organise online shopping and visits.) We also encourage colleagues in other parts of the council, health services, housing and other organisations to identify and support carers at an early stage. This could range from a GP identifying carers, when carrying out a health check and referring them to universal services; to a member of staff at an Idea Store showing a Carer where to find the universal services available to them to a Housing Officer knowing when to refer a Carer to adult social care for an assessment.

Tower Hamlets Carers' Centre plays a key role in helping to identify and support carers. It provides advice, information, support services and independent advocacy to all carers within the borough. Support services include:

- Help with benefits
- Group and one-to-one support
- Bereavement counselling
- Activities and outings
- Retreats/respites
- Alleviation and management of stress
- Case work and advocacy support to "speak out"
- Training

The Carers' Centre is the key resource in helping carers to carry out their own self assessments for people who may need more intensive or ongoing support from the council. These assessments are based on a discussion about the kinds of issues the person need help with, the impact these issues have on their life, and how they can be addressed. The Carers' Centre currently helps carers complete these self-assessments

The Carers' Centre is included under the heading "Local Link", and is the main information and advice "hub" for carers. The Assessment and Intervention team can be contacted if a Carer is in need of a Carer's Assessment or if there are safeguarding concerns.

What are we going to do

Feedback from carers and professionals tells us that people often don't recognise themselves as carers for a number of reasons and this can prevent people from getting access to information, advice and support at an early stage. We therefore need to find other ways to identify those carers who need support, and ensure they get that help early on to stop any problems escalating into crises. Feedback from carers suggests that the systems in place to help identify carers are more reactive, with Carer's Assessments only happening when a person presents themselves at a point of crisis. A more proactive model will be developed, which will focus on prevention and include outreach workers and a community-based system for new carers that will involve experienced carers who can share their knowledge.

Involvement and engagement work with carers has also revealed that they believe more work needs to be done to train social workers on how to identify and work with carers. The new adult social care practice framework helps to facilitate these discussions by providing for a whole family approach to assessment. This means that social workers take into account the needs of the whole family when assessing the needs of the person in need of a service. However, feedback suggests that further training is needed in how to best use this new practice framework to identify carers who do not recognise themselves as such.

There is a greater role for GPs and other health 'gateways' to play in early identification and intervention for carers. We know that caring, particularly unsupported caring, impacts negatively on people's health, and increases demand for health services. Yet current health services may be treating these health 'symptoms' of caring, without identifying and/or addressing the cause. We will ensure that health and social care services are better linked up to help encourage greater identification. This will include a 'single point of access' for carers into health and social care services, and linking into existing integration work currently being developed as part of Tower Hamlets Together, such as Wellbeing Hubs that will be set up at Idea stores in Tower Hamlets to signpost people to services that support issues such as education, training and employment and loneliness. This could be extended to include Carers' support services. Emphasis will also be placed on the practice framework for social workers to ensure that the mechanisms in place to identify carers are

being used effectively and that any identified support needs for carers are being responded to at an early stage.

Feedback from Tower Hamlets Carers' Centre is that support must be timely, and that self-assessments which have been referred to the council, take too long to be addressed, with carers waiting for long periods of time without knowing what their status is, or whether they are eligible to receive services. This has an effect on their caring role, and whether they are able to continue to provide care. It was reported that some carers have been waiting for more than three months. Carer assessments need to be completed in a timely manner.

Young carers – Identification and Recognition

What should we be doing?

The Children and Families Act 2014 states that the local authority has a duty to assess whether a young person within their area has needs for support. The major change in this legislation is that young carers no longer have to request an assessment. This should be carried out based on an appearance of need. The Young carers (Needs Assessment)⁷ Regulations 2015 outline the key features of a Young Carer's Assessment.

Young carers are entitled to an assessment under this legislation. It is vitally important that all professionals who come into contact with young carers, whether in their work with the young person themselves, with the cared for person, or in some other way, support them to access assessment and provision.

⁷ Young Carers (Needs Assessment)⁷ Regulations 2015 SI 2015/527

The assessment must determine:

- the amount, nature and type of care which the young Carer provides (or intends to provide);
- the extent to which this care is (or will be) relied upon by the family, including the wider family, to maintain the well-being of the person cared for;
- whether the care which the young carer provides (or intends to provide) impacts on the young Carer's well-being, education and development
- whether any of the tasks which the young Carer is performing (or intends to perform) when providing care are excessive or inappropriate for the young Carer to perform having regard to all the circumstances, and in particular the Carer's age, sex, wishes and feelings;
- whether any of the young Carer's needs for support could be prevented by providing services to
 - the person cared for, or
 - another member of the young Carer's family;
- what the young Carer's needs for support would be likely to be if the Carer were relieved of part, or all, of the tasks the young Carer performs (or intends to perform) when providing care;
- whether any other assessment of the needs for support of the young Carer or the person cared for has been carried out;
- whether the young Carer is a child in need; any actions to be taken as a result of the assessment; and
- the arrangements for a future review.

What are we currently doing?

Requests for support are currently considered by the Council's Multi-Agency Safeguarding Hub (MASH). It is rare for a referral to be received for a young Carer purely on the basis of their caring responsibilities. It is more common that these are picked up as part of an assessment. Once a young Carer is identified, there are a number of pathways that could be followed in order to address the need. These include exploring additional support from within the family, via a family meeting, or a referral to some of the provision that is already available.

Children who meet the criteria to be allocated to the Children with Disabilities Team will automatically qualify for one "short break". Should the family request more, this will trigger a Child and Carer's Assessment which will identify the additional needs of any other children within the home. Currently this assessment only takes place when a family requests additional support.

Some Tower Hamlets schools are involved in a project run by Family Action and commissioned by the Council to better identify and support young carers within their schools. Schools are best placed to meet the needs of the young

people who attend them. They know their students well and are able to ensure that they meet their needs of students in a sensitive way. The schools programme gives individual schools access to support from Family Action to support with identification and meeting the needs of young carers. Schools will draw up an individual action plan and will commit to raising the profile of the issues that affect young carers. One of the schools to complete the programme was Cubitt Town Primary School. More information about their story can be found in the case study below.

Cubitt Town Primary School

Cubitt Town Primary School has well-established learning mentor provision within the school, so when it was asked to become accredited for the support that they provide to young Carers, this felt like a natural step to take.

There are currently three identified young Carers within the school, who receive support specifically because of their role as young Carers. However, there are some other children who are being monitored and supported, where caring responsibilities may become more of an issue as they get older.

The young Carers come together as a group on a regular basis to access support from the learning mentor, as well as to support each other. They also act as Young Carers' Ambassadors and there is an annual assembly. This assembly enabled one young Carer within the school to self-identify.

Staff in the school have also been trained to provide training to other staff members. Cubitt Town Primary School is the first Tower Hamlets School to complete the accreditation process.

While there is research which outlines the positive impact that taking on a caring role can have, there is an increasingly strong body of evidence which notes the adverse effects that caring for another person can have.

There is evidence that suggests being a young Carer can have an “adverse impact on children’s lives and transitions to adulthood, particularly when caring is long-term, unsupported and disproportionate to the children’s age and level of maturity”⁸

Research also shows that caring affects a child’s ability to participate in school and decisions on whether to continue into further and higher education.⁹

⁸ Aldridge (2008) As referenced in the report to the Department for Education “The lives of young Carers in England - https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/498115/DFE-RR499_The_lives_of_young_Carers_in_England.pdf

⁹ Becker (2007) as above

The Children's Society carried out a longitudinal study "Hidden from view – the experiences of young carers in England" in 2013¹⁰ which shows that young carers have significantly lower educational attainment at GCSE level - the equivalent to nine grades lower overall than their peers (e.g. the difference between nine Bs and nine Cs). Young carers are also more likely than their peers to be not in education, employment or training (NEET).

The Young Carer's Steering Group currently keeps a register of young carers. The vast majority of those on the register are caring for people with a mental health condition. CHAMPS is a service for children based with the Adult Mental Health service, due to this position it is well placed to identify and support young carers and has worked hard to raise awareness of the impact that caring can have on children and young people. More needs to be done to replicate this across services for adults with a physical and learning disability, as well as those with substance misuse issues.

What will we be doing in the next 3 years?

Currently there is no specific assessment form for young carers. From September 2016 a pilot will be rolled out, whereby a small number of young carers will be assessed using the MACA and PANOC assessment tools.

The Multidimensional Assessment of Caring Activities (MACA-YC18) is a short questionnaire designed to establish the extent of the caring activity being undertaken by a young person.

The Positive and Negative Outcomes of Caring (PANOC-YC20) is a short questionnaire designed to help young carers to understand the emotional impact of caring.

There is a clear need for an assessment pathway, produced in conjunction with young carers. The exact format of this assessment will need to be decided, including any learning from the pilot project, but the MACA and the PANOC will be considered as part of this.

One of the key areas that require further development is where young carers are identified by an agency working with the cared-for person. In many instances this would be the council's Adult Services but it could also be health partners or those in education, where a young person is caring for a sibling who is also a child or young person. Currently, the referral pathways do exist but are not widely used. A major aim of the action plan will be to encourage all agencies to think about carers when working with service users.

The Associations of Directors and Children's and Adults' Services (ADSC & ADASS) have released an updated Memorandum of Understanding¹¹. This

¹⁰ http://www.childrenssociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-Carers_final.pdf

¹¹ ADSC & ADASS, 2015, No wrong doors: working together to support young Carers and their families,

document outlines a number of key principles; the main one being there should be “no wrong door” for young carers and their families. Regardless of which service they approach for support, they should be identified, assessed and provided with support. Tower Hamlets has signed up to a previous version of the memorandum but should do so again in relation to the updated version.

The Children and Families Act 2014 requires a level of proactivity in identifying young carers, closer working with colleagues across the partnership should enable an earlier identification of young carers and a referral to MASH for assessment. The Children with Disabilities Team currently carries out Child and Carer’s Assessments when additional support is requested. Such assessments should be carried out regardless of whether support is requested.

Young carers must also know of their right to request an assessment. This is a gap that must be urgently addressed. It is important to recognise that many young carers and their families will be reluctant either to acknowledge their role or seek support, for fear of Children’s Social Care involvement. It is essential that any help that is offered is seen as supportive rather than punitive. It is also likely that some young carers, particularly those who care for people with substance misuse issues, will not identify themselves as carers at all and will often be particularly fearful of any kind of social care intervention.

The poorer outcomes that research indicates affect young carers will also need to be addressed. Often, young carers are not identified at an early enough stage, if at all, which makes it very difficult to put in place the additional support they need to achieve in line with their peers. Earlier and better identification is essential in addressing this.

A training programme is being considered to ensure that social workers across both Adults’ and Children’s Social Care have a greater awareness of young carers and their needs. This will support in identification and recognition, as well as ensuring that our other aims for young carers are met.

Priority 2: Realising and releasing potential

This means we will aim to support people with caring responsibilities to fulfil their education and employment potential.

What carers have said

"I cannot work, as my partner needs full-time care."

"I know a lot of carers here [Carers Centre] who have to give up work, due to the lack of flexibility and support offered to them by their workplace. They all want to continue working, but without the support and understanding of their employers ... and adequate input from social care and health services to ensure their family member is safe and being well cared for, this is often not possible."

"Employers, particularly the private sector, do not always understand the dual role of the working carer."

"I'd love to learn new skills (e.g. computer skills) but cannot always find the time to access courses available"

"Sometimes, I just can't get my homework done on time. I wish my school were a bit more understanding."

We need to empower carers to fulfil their work potential, to protect their own and their families' current and future financial position and to enable them to enjoy the health benefits and self-esteem that paid employment or self-employment can bring.

What should we be doing?

Enabling young and adult carers to fulfil their educational potential

Inappropriate caring roles or long hours of caring for young carers are likely to have a detrimental impact on their lives, including their health and educational achievement. Young carers should be supported to achieve their potential and to have the same opportunities that other young people enjoy. Adult carers should also be supported to pursue education, training, work or leisure activities, if they wish, and these aspirations should be taken into account when assessing a Carer's need for support.

Support for carers of working age

It is crucial that we place a much higher priority on supporting people of working age with caring responsibilities to remain in work, if they wish to do so. We need to empower carers to fulfil their work potential, to protect their own and their families' current and future financial position and to enjoy the health benefits and self-esteem that paid employment or self-employment can bring. However current feedback suggests many carers currently feel forced

to give up work because they feel they have no other options available to them.

Carers have cited flexible working as one of the most important factors in allowing them to juggle paid work, their caring responsibilities and family life.

Carers have also fed back that they feel the skills they learn from caring should be recognised once their caring role is over and they should be supported to turn these skills into recognised qualifications that will enable them to be employed in the health and social care field.

What are we doing?

Evidence from the 2011 Census reveals fewer carers in Tower Hamlets were economically active than the regional and national averages (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%, compared to 6% in London and 4% in England).

Respite and replacement care play an important role in supporting carers in employment. Tower Hamlets' Adult Social Care currently funds both replacement care, in the form of short-term, home-based care (typically provided by a home care organisation¹²) and short residential care. Short-term residential breaks are provided at Hotel in the Park (HITP) for adults with a learning disability, which is a seven room residential facility in Bethnal Green. Service users can book in for a number of allocated days, giving respite to their regular carer, enabling them to stay in employment. Equivalent arrangements are not in place for people who do not have a learning disability: in those instances, beds in residential or nursing homes are booked, if available. A service user with a personal budget in the form of a direct payment may also choose a different organisation or individual to provide replacement care.

Feedback from carers and professionals suggests some people are experiencing problems when organising respite. Tower Hamlets' Carers' Centre has reported that many carers have to take time off from employment for emergency care of people they care for because respite and replacement services have not been working as well they should be.

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 obtain work experience and gain a diploma qualification in health and social care. This programme is available for women who have been out of work caring for their loved ones.

¹² Current providers: Age UK, APASENTH, St Hilda's Community Centre and Jewish Care

What are we going to do?

We will develop a new 'Carers' Charter' which will be co-produced with carers in Tower Hamlets. One requirement of this charter will be for local employees to recognise flexible working options, which should be available to employees with caring responsibilities to help support them to carry on working alongside their caring role.

Young carers - Reaching and Realising Potential

What should we be doing?

The assessment of children and young people under the Children and Families Act 2014 is a vital tool in ensuring that children and young people who are young carers are able to realise their full potential. Research tells us that caring has an adverse effect on young people's educational attainment and any assessment of a young person should include a focus on ensuring young carers remain in education or training and are able to achieve.

Schools should also make attempts proactively to identify young carers and, where appropriate, make additional support available to them to ensure that they fulfil their potential.

The Children's Society published a report into the impact that caring can have on young people, entitled "Hidden from View – the experiences of young carers in England"¹³. This outlined a number of key findings including:

- one in 12 young carers is caring for more than 15 hours per week. Around one in 20 misses school because of their caring responsibilities.
- young carers are 1.5 times more likely than their peers to be from black, Asian or minority ethnic communities, and are twice as likely to not speak English as their first language.
- young carers are 1.5 times more likely than their peers to have a special educational need or a disability.
- the average annual income for families with a young carer is £5,000 less than families who do not have a young carer.
- there is no strong evidence that young carers are more likely than their peers to come into contact with support agencies, despite government recognition that this needs to happen.
- young carers have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall than their peers (e.g. the difference between nine Bs and nine Cs).
- young carers are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19.

¹³ The Children's Society (21013). Hidden from View, the experiences of young Carers in England. http://www.childrenssociety.org.uk/sites/default/files/hidden_from_view_final.pdf

The report also identified a number of characteristics of the type of households where young carers are more likely to be found.

Factor	Relationship
Family income	The median family income for families including a young carer was £5000 less than families without a young carer
Adults in the household in work	Young carers are over four times more likely to live in a household where no adults are in work
Maternal education levels	Young carers are 1.6 times more likely to have a mother who has no educational qualifications
Adults with a limiting disability	Young carers are over twice as likely to live in households where at least one adult has a limiting disability
Number of children in the family	Young carers are 1.6 times as likely to live in households where there are three or more other children living

The understanding of the type of circumstances where young carers are more likely to be found is useful in the identification of young carers.

What are we doing?

A number of schools, both primary and secondary, are engaging with a programme run by Family Action to provide better support to young carers. One of the key elements of this programme is ensuring that young carers receive additional support to meet their educational goals. This programme is currently run in a small number of schools, but the hope is that this could be rolled out more widely. When children are missing school for whatever reason, they will be provided additional support from within the school as well as the council's Attendance and Welfare Service. This will seek to understand the reasons for the absences and put strategies in place to address them. If the young person's caring responsibility is found to be a reason for poor school attendance, then action could be taken in order to address this, including referrals to either Children's or Adult Services.

Assessments carried out within Children's Social Care will consider the educational needs of a young carer. If concerns are identified, appropriate support will be sought, in order to ensure that young carers are able to achieve in line with their peers.

One of the key priorities within the Tower Hamlets Children and Families Plan 2016-2019¹⁴ is to help young people to reach their full potential. One of the key actions included within this priority is to "Continue to reduce the number of young people not in education, employment or training through early intervention and tailored support".

¹⁴ Children and Families Plan (2016) <http://www.childrenandfamiliestrust.co.uk/wp-content/uploads/2010/09/2016-19-Children-Families-Plan1.pdf>

What are we going to do?

Up until now, young carers have not had the additional focus that is available for other vulnerable groups, such as looked after children. The Young Carers' Steering Group should give consideration to how to ensure that young carers are able to achieve to their full potential and go on to higher education. Where caring is having an impact on school attendance, we will seek to further understand this and the Attendance and Welfare Service will support parents and carers to address this issue.

Schools have a major role to play in addressing this and the expansion of the Family Action programme, along with further awareness-raising across the partnership will be an important step in ensuring that the needs of young carers are met.

The Children and Families Plan has been approved for the next three years, in which time the focus of the action will be to support young people with caring responsibilities to ensure that they are able to meet their full potential.

Priority 3: A life alongside caring

This means we will aim to provide personalised support to both carers and those they care for, enabling them to have a family and community life.

What carers have said

“I don’t see my friends as much.”

“I need a break for my own wellbeing and to help support the rest of my family.”

“Personal budgets and direct payments are great ideas but it’s too much hard work ... we don’t want more paperwork”

“Young carers are always helping others. It’s important to make sure that they have a space where they can have time to themselves.”

“Sometimes I just want a bit of time to play on my phone or watch videos on YouTube”

A break from caring was an issue that was discussed at length during the consultation and one that carers identified as important to them. They were clear that time away from their caring role was needed for them to maintain it. Many respondents stopped socialising regularly and were prevented from going on a holiday. However, feedback suggests current opportunities within day services and respite is not flexible enough.

Being made to feel guilty about wanting this time away was a common theme cited during consultation. However carers said that it was just important for their own wellbeing and to support other members of their family.

What should we be doing?

Personalising support for carers and the people they support

Families and individuals are investing more of their own time and financial resources in caring, and are often providing complex and intensive levels of care. It is of crucial importance that we consistently keep in mind the potential impact of caring on the lives of carers, in particular the impact on their health and well-being; education and employment opportunities; social life and social inclusion; and both individual and family finances. We know that the circumstances of individual carers vary enormously, and this means that a one-size-fits-all approach to support will not deliver the outcomes that matter most to carers and their families. Personalising support so that it fits around the lives, goals and needs of the Carer is critical to supporting them personally, both as part of their caring role, and in maintaining their own health and well-being

Availability of good quality information, advice and support

Information and advice is needed to address different aspects of caring at different times during a caring pathway, and there is a need to ensure that support is tailored to individuals' needs. Carers may want help to develop skills and knowledge to care effectively and may want advice and support to look after their own health and well-being and that of their family while caring for someone else. The Care Act 2014 places a new duty on local authorities to provide information and advice to help carers understand how care services work, what services are available locally and how they can be accessed.

There is a lot of information available to support people who have caring responsibilities but we know from feedback from carers in the borough that many families are unaware that such information exists or still struggle to find information and advice that is relevant to their particular needs for support, including financial support. Carers have told us that finding the right information for them when they need it can cause much frustration and make stressful situations even more stressful, particularly when trying to arrange care and support quickly. Feedback from carers and professional across health and social care services show that carers are often accessing services at the point of crises. The provision of good information and advice at an early stage will help carers to access support before they reach crisis point.

It is important that carers and families have time to think through their options and make informed decisions about their own lives alongside caring, including decisions about remaining in education or paid employment, claiming benefits and contributing to pensions. Early access to information and advice and, where appropriate, early intervention rather than waiting until a crisis occurs, are key elements in supporting people to undertake caring roles effectively. Early interventions to guide families to information, advice and support as soon as they start to care can help people identify practical support, think through the options for remaining in paid employment or education, manage other family commitments alongside caring, and reduce the likelihood of falling into financial hardship.

What are we currently doing?

The new approach to social care assessments in Tower Hamlets is now focused on outcomes rather than just service provision. Therefore, individuals will be asked specifically what outcomes they would like to achieve. Examples of outcomes could be around the Carer's ability to take up training or education. In such a case, support might include giving time off through respite, or paying for and supporting carers to enrol on training courses, or signposting to the types of educational programmes carers are interested in.

The local authority will assess what those needs carers may have. This assessment will consider the impact of caring on the Carer. It will also consider the things a Carer wants to achieve in their own day-to-day life. It must also consider other important issues, such as whether the Carer is able

or willing to carry on caring; whether they work or want to work, and whether they want to study or do more socially. If both the Carer and the person they care for agree, a combined assessment of both their needs can be undertaken.

We will agree a support plan with carers which set out how the Carer's needs will be met. This could include, for example, help with housework or buying a laptop to keep in touch with family and friends. It may be that the best way to meet a Carer's needs is to provide care and support directly to the person they care for, for example, by providing replacement care to allow someone to take a break from caring. It is possible to do this as long as the person needing care agrees.

Carers who have eligible needs are able to access personal budgets. Personal budgets are available to carers in the form of direct payments and can be used in a number of different ways to help support the caring role. Examples include:

- travel expenses or fees to take up leisure or education activities
- health promotion activities, such as exercise classes, gym membership, massages or relaxation or complementary therapies
- practical things, such as a washing machine or a computer
- respite care for the person they look after, to give them some time to themselves
- a short holiday to recharge their batteries
- driving lessons
- help with housework and gardening
- a mobile phone
- leisure classes to relieve stress.

For parents who are caring for a child with a disability, the opportunity for respite is a necessary and valued part of any child's care package. These short break placements give the opportunity for the child to experience different types of activities than would be available to them at home. It also gives a much-needed break for parents, often making the caring responsibilities more manageable.

Up to date information about services to support carers has been identified as a fundamental issue. The council's website is in the process of being updated and Local Link 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 services in Tower Hamlets specifically for carers, including the local Carers' Centre 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 benefits and rights.

The Information Plan for carers is consistent with the Information Plan in Adult Social Care, which sets out how we will improve our information and advice. The four objectives of the Information Plan are:

- to ensure adult social care information provision is meaningful and accessible to the whole population of Tower Hamlets.
- to reduce or delay the need for adult care and support through the provision of information and advice.
- to empower and people to make informed decisions in adult social care through information and advice.

What are we going to do?

Carers have highlighted to us that some people have been caring for so long, or caring has taken up so much of their lives, that it is difficult for them to see what life there is outside of their caring responsibilities. This means carers may find it difficult to decide on what they could do with their spare time. Therefore, when completing self-directed assessments; assessors will be instructed to consider offering options and ideas to carers on self-development, or self-fulfilment. However, this offer will not exceed realistic expectations and raise hopes of amenities that cannot be granted. Carers have told us that, in the past, after being assessed by council staff that they have been promised services that were later denied, as they fell out of the scope of what was on offer, or they were not eligible. Some were even directed to the wrong services. We will ensure that the council trains staff to carry out Carers' assessments effectively, and to be well informed of the range of services that are on offer, but also not to over promise, and raise false hopes and expectations.

We know that one area of concern for organisations that provide Carers' services is the way the council has commissioned respite care. They feel that council processes on granting respite care services have not taken into consideration the complex needs of carers. The Carers' Centre cited an example where many carers have to take time off from employment for emergency care of people they care for. They reported that respite services have not been working as well they should be. Carers in Tower Hamlets have also reported this to us. We will explore the possibility of considering respite services on a more individual basis in order to understand the complexities of needs. The council recognises this area needs further development.

Many carers fed back that they felt that leaflets, guides and other published information about services for carers were hard to understand, and the information about services was not integrated. For example, many carers could not distinguish the difference between social services and health services, and so are at risk of falling through the system. They said that publications should have a description of the various services, and what they offer. Carers would prefer access to centralised published information about services, including booklets. We will review the current materials available on council and partner services, and ensure publications are readily accessible, easy to read, and provide succinct information about the range of services that are available, both from the council and local providers of services to carers.

Young carers - A life alongside caring

What should we be doing

Under the Care Act 2014, the rights of carers are equivalent to the rights of the people they care for. As part of any Young Carer's Assessment, there should be consideration of the type of activities that a young Carer would like to engage in and appropriate referrals made.

If a young Carer has a large caring role it is likely that respite care would be appropriate but it is important to consider carefully how to provide this. Many young carers carry out a monitoring and company role, rather than a significant amount of physical activity. The emotional impact of leaving the person they care for either alone or with someone else should not be underestimated when identifying both respite and additional activities for the young Carer.

There are many practical difficulties in arranging outside activities for young carers, which need careful consideration. It may be necessary to provide sitting services for the cared-for person and to reassure the young Carer that their loved one is well looked after. It may also be necessary to consider transport as young carers - particularly those of primary school age - may struggle to access provision without it.

What are we currently doing?

The Young Carers' Project is an activity-based group for young carers, aged between 8 and 18. The aim of the project is to offer a weekly short break session for young carers which would enable them the opportunity to meet, share experiences and engage in structured, fun activities.

If additional needs are identified, then a referral can be made to the Targeted Youth Support Service which is able to provide more individualised support for young people who meet the relevant criteria.

Children and young people who have a sibling with complex needs often take on a higher level of caring responsibilities than their peers, either for themselves or their siblings. The short breaks that are offered to the cared-for child will provide the opportunity for young carers to spend more time with their parents and be relieved of some of the additional caring activity that they are taking on.

Tower Hamlets has a very active voluntary sector and there are organisations which are able to provide a range of support and activities to young carers. Currently, this support is not well understood by the services which would be making referrals, and further work is required to ensure that these services can be accessed by those who require them.

What are we going to do?

Better identification of young carers will enable us to understand the needs of this group of young people. Experience from other places tells us that a significant group will benefit from additional activities that will get them out of the home and away from their caring activities. Young carers can be as young as five years old. It is important that any provision is available for all young carers, regardless of age.

It is likely that additional services will need to be identified and provided, either through commissioning or working more closely with the voluntary sector. Young carers are entitled to activities and support that meet their needs in exactly the same way that any other vulnerable young person is. At the moment, this support is not always provided, which is a gap that must be addressed.

DRAFT

Priority 4: Supporting carers to stay healthy

This means we will aim to support people with caring responsibilities to remain mentally and physically well.

What carers have said

“It is stressful to care for someone you love.”

“I have my own physical health problems. Some were conditions which occurred over time; others were as a result of moving and handling my husband.”

My caring role often leaves me feeling tired. I have a lot of anxiety worrying about the future and worrying about finances.

Carers have described how the caring role can often have a detrimental impact on their own health and wellbeing. Carers admitted that they readily neglect their own health, because they are so busy supporting someone else. Particular concern was expressed for older carers who are often housebound and lack mobility.

What should we be doing?

Reduce the impact of caring on health and well-being

Carers in Tower Hamlets have told us that, while caring can be very rewarding and fulfilling, it can also be emotionally and physically draining. We know that many carers, in addition to anxieties about the health of the people they care for, can experience significant stress caused by the extent and nature of their caring responsibilities, balancing caring with education or paid employment, the state of their family finances and concerns about the quality, quantity or reliability of care and support provided by others.

Carers highlighted the importance of regular breaks from caring responsibilities to help them look after their own health and well-being and to sustain them in their caring role. There is a clear relationship between poor health and caring that increases with the duration and intensity of the caring role. The 2011 Census demonstrates that the general health of carers in Tower Hamlets deteriorates incrementally with an increase in the number of hours of care provided. The data highlights that 5% of carers reported that their health was ‘not good’, which increased to 16% amongst those delivering over 50 hours of care per week. The 2011 Census highlighted that young men, up to the age of 24, caring for over 50 hours a week, reported four and a half times more poor health than their peers. Carers have told us that that timely, flexible and quality support can help those with caring responsibilities to look after their own physical and mental health at the same time as supporting others.

Prevention and early intervention for carers within local communities

Access to relevant information, at the right time, is crucially important for all carers. Information and focused support at key stages along the care pathway, for example when a diagnosis is made, at the time of hospital discharge or at the end of the life of the person they have cared for, can improve health outcomes and experience for carers.

Carers should be supported to pursue leisure and sport activities and to access local NHS and local authority public health services, such as weight management and smoking cessation sessions, in order to maintain their physical health. It is also important for carers to be supported to look after their own mental well-being and maintain and develop social contacts.

Supporting carers to look after their own health and well-being

Carers often feel they do not have time to look after their own physical and mental health. As well as being supported to take breaks from caring responsibilities, it is important that carers are supported to have their own health checks and to attend appointments for maintaining good health, including dentist and optician appointments, as well as being supported to attend to their own health problems and long-term conditions in a timely and convenient way.

Poor mental and physical health are often associated with caring for someone at the end of their life and during a period of bereavement, so it is also important that people receive support to cope with the end of a period of caring. Many carers feedback that bereavement services play a key role in helping them transition from the caring role, once it has ended.

What are we currently doing?

As part of their wider responsibilities, local authorities have a duty to take a proactive approach to meet the needs of people, make earlier interventions and provide more services that are intended to prevent, delay or reduce the need for care and support. This means carers need to be supported early on to prevent them reaching crisis point. It is important to consider what it is we are trying to prevent happening to carers. Based on what we know and what carers have told us, the main things we are trying to prevent include carers feeling overwhelmed with stress, anxiety or worry, carers developing physical or mental health problems, and carers feeling that they have no time to themselves or life of their own. Ultimately, we are trying to prevent carers getting to the stage where they either need support themselves or feel they cannot continue in their caring role. We currently do this by:

- encouraging staff to identify and support carers at an early stage
- improving our information and advice, with a view to carers having queries and problems resolved quickly before they escalate
- commissioning a range of services available to all carers, aimed at supporting them to stay well. This includes 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/respite care and improve the system used to book this.

- tapping into and promoting a range of existing projects that carers can benefit from. This ranges from public health initiatives such as support to stop smoking to social care initiatives such as assistive technology
- ensuring risks and issues are addressed by practitioners. Our Practice Framework puts an emphasis on having a holistic view of the support networks available to people in support planning. Clear and detailed contingency plans also form part of this, and are important in identifying what needs to happen should an emergency occur.

This is primarily communicated through the Council website and Local Link, but is also communicated through people and places who routinely come into contact with carers. This is part of the Information Plan for adult social care.

What are we going to do?

One of the most significant issues that affects the health and wellbeing of carers is supporting the cared-for person to move around on a regular basis. Many carers are not aware of safe techniques and ways of moving people around and therefore gradually start to suffer from physical pain. A carers Centre service user survey found that half of its carers have physical health problems, such as bad backs, bad knees and joint pains. The majority of these issues have been found to be linked to their caring roles where they are regularly required to move around people they care for. Amongst other provision, we will enable access to manual handling training through the development of a Carers' Academy to prevent long term harm and injuries to carers.

Young carers – Supporting carers to stay healthy.

What should we be doing

Any assessment of a young Carer should include an understanding of their health needs. School nurses will have an important role to play in this. The Department of Health and Department for Health have jointly developed an education programme¹⁵ for school nurses in relation to young carers. This document outlines the strong focus that school nurses should have in ensuring that the health and wellbeing of young carers is promoted. School Nurses are commissioned via the Public Health service within the council and it is therefore possible to reinforce this as a priority within the school nursing teams.

¹⁵ Supporting the health and wellbeing of young Carers (2011)-
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299270/Young_Carers_pathway_Interactive_FINAL.pdf

Young carers are more likely than other young people to be not in education, employment or training (NEET). The Department for Education recognises that *“being NEET is associated with negative outcomes later in life, including unemployment, reduced earnings, poor health and depression. These outcomes have a cost for both the individual and the economy.”*¹⁶

It is important to tackle the issue of young Carers’ access to education and employment. However, it is also essential to ensure that where these health conditions exist they are addressed and the young person has the support that they require.

Adult carers report difficulties in accessing universal healthcare provision at times, due to their caring responsibilities. This is something that is equally acute for young carers, and partners in Health need to consider how best to meet the health needs of young carers. GPs have the ability to identify on their systems whether a person is a Carer or not. Currently, this is recorded in approximately 11% of cases. Fewer than 3000 people are recorded as carers on the GPs system, which is a significant under-recording.

What are we currently doing?

Any assessment that is carried out in respect of a young Carer will include a focus on their health needs and ensuring that these are promoted. Any plan that is put in place, whether it is “Team Around a Child” (TAC) or “Child in Need” will include the whole network, which means that school nurses will be aware of the young carers on their caseloads and be able to provide some additional monitoring and support.

The link between caring and subsequently becoming NEET has been acknowledged, as has the link between poorer health outcomes. These will be addressed as part of the action plan within the Children and Families Plan 2016-2019.

What are we going to do?

By raising the profile of young carers across the partnership, this strategy aims to address the poorer health outcomes that impact on the lives of young carers. All GPs will routinely record whether a person is a Carer or young Carer in the health records and be able to offer a service which better meets the needs of all carers.

¹⁶Department for Education (2016)
<http://www.education.gov.uk/childrenandyoungpeople/youngpeople/participation/neet>

Priority 5: Transitions

What should we be doing

The Care Act places a duty on local authorities to assess adult carers before the child they care for turns 18, so that they have the information they need to plan for their future. This is referred to as a Transition Assessment. The Care Act places a duty on local authorities to conduct a Transition Assessment for an adult carer where it appears that the carer is likely to have needs for support after the young person they care for turns 18, and where they think that there would be 'significant benefit' to the carer in doing so.

The planning for transition should start at the earliest possible stage, ideally by the age of 14. Carers have told us that while they understand that the age of the cared-for person is very important within the council context, it is much less so to them. The transition between Children's and Adult Services should therefore be as seamless as possible and where at all possible the package of support should remain in place, with any changes made in a plain and gradual way.

The time of transition can be very uncertain and worrying for both the carer and the cared-for person. Planning and preparation from an early stage is crucial to minimising the stress that this change can cause.

Young carers under the age of 18 who care for an adult will continue to be supported by Children's Services rather than Adult Social Care. At the age of 18 Adult Social Care will take over the responsibility, although it can be brought into the transition planning before the young Carer's 18th birthday, but only at the young Carer's request. There is a new duty to continue with any services a young Carer is receiving past the age of 18, if appropriate adult care and support is not in place.

What are we currently doing?

A child who meets the criteria to be allocated a social worker within the Children with Disabilities Team (CWD) is likely to meet the criteria for support through the Community Learning Disability Team (CLDS). Planning for transition starts within the CWD team when the child turns 14 and continues until the transition takes place at age 18. One of the main difficulties is that the CLDS does not come on board at such an early stage and often not until just before the young person turns 18. This delay often leads to significant uncertainty for the service user and their parents, particularly when the decision relates to residential placements and packages of care.

What are we going to do?

Transition is a complex area, covering many areas within both Children's and Adult Services, including but not limited to carers. It is clear that this is an issue that causes anxiety to carers and service users and it is a focus for senior management across both directorates to improve this process.

Conclusion

This strategy has pulled together national legislation, local data, Carer and professional feedback to generate a summary of the need in Tower Hamlets and provides the strategic framework for how carers will be supported in Tower Hamlets over the next three years.

Identification and recognition is vital to supporting more carers in Tower Hamlets. How we do this will be a key priority moving forward over the next three years, as we know there are lot more carers out there than those currently accessing carer support services. Enabling these carers to access support services that help to provide them with a life alongside caring; to access employment so they can better support their families and to remain healthy is the main aim of this strategy.

Young carers have the potential to be very difficult to identify and support. Often they will not understand that they are in a caring role or may be reluctant to ask for help and support. Professionals need, therefore, to make sure that, through better identification and recognition, young carers are able to achieve their potential and lead healthy and active lives. Schools will play a key role in this process but all agencies that come into contact with a young Carer must ensure that the support they offer makes a real difference to their lives.

The Children and Family Partnership is determined proactively to identify and support young carers to have the best quality of life possible and to achieve to their full potential. This strategy outlines how we intend to do this.

Delivering the priorities highlighted in this strategy will have its challenges but there is a clear commitment within Tower Hamlets to achieve them. The next steps are to co-produce an action plan with local carers in that will address the issues outlined in this strategy. This will be co-produced with carers to ensure that it fully addresses their needs. The action plan will describe our intention to deliver within identified budgets, and will be in line with our key priorities. It will be monitored regularly to ensure progress and a full report will be provided at the end of the term of this strategy.