# **Health Scrutiny Panel**

# Unpaid Carers Scrutiny Challenge Session



London Borough of Tower Hamlets May 2015

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Carers play a key role in our community, as they do across every community and society. However, many carers, whether young or old, are sometimes left without adequate support in their caring role. Carers left unsupported may miss out on the opportunities life has to offer, therefore affecting an individual's capacity to engage in education, social life and personal relationships.

The council and services for carers in the borough have been developing innovative ways of working with carers in a challenging landscape, to enable carers to lead fulfilling lives and provide the right level of support they need in order to do so.

To support this work we have made nine recommendations in this report, which we feel needs consideration to support carers in their caring roles, especially in light of changes to the Care Act 2014, and the development of a new local Carers Plan.

We hope these recommendations will help to enhance our current Carers Plan, and address issues that are common to carers across the spectrum.

Councillor Asma Begum Chair, Health Scrutiny Panel, 2014-15

#### 2. Recommendations

#### **Recommendation 1:**

That the Carers Plan be developed in partnership with local carer service providers, carers' forum and in consultation with local carers.

#### **Recommendation 2:**

That carers assessments are completed in a timely manner to ensure carers are supported to continue in their caring role.

#### **Recommendation 3:**

That the council's social care staff are trained to support carers effectively by being aware of various services available in the borough to support carers including information, advice and guidance. This should also include managing expectations of carers.

#### **Recommendation 4:**

That carers are provided clear and substantive feedback when they are not eligible for services and appropriately signposted to universal and preventative services they can access.

#### **Recommendation 5:**

The range of carers services available are publicised on the internet. We will review our investment in those services in response to feedback from carers through the assessment process and ensure that any new provision is appropriately publicised and that carers and relevant organisations are made aware of such changes.

#### **Recommendation 6:**

That the council in partnership with Tower Hamlets CCG develop a manual handling training course for local carers to prevent long term harm and injuries to carers.

#### **Recommendation 7:**

That consultation and engagement be undertaken with carers to better understand need for respite services and ensure these are designed to meet local needs.

#### **Recommendation 8:**

That work is undertaken by primary health care service and the council to help carers that do not recognise their role as carer to better support them to enable them to continue with their caring role.

#### **Recommendation 9:**

That welfare benefit support to carers is strengthened to ensure carers are accessing all available benefits that they are entitled to and do not have additional financial stress.

# 3. Introduction

- 3.1. Carers are one of the main resources supporting the health and social care economy in Great Britain. There are six million carers nationally with over a fifth of these carers providing more than 50 hours of care per week. Providing effective and relevant support to carers is a key mechanism to ensure carers are able to continue in their caring role. This includes improving the quality of life of carers by allowing them to have a life outside of their caring role, enable them to achieve their education and employment ambitions and support carers to remain mentally and physically healthy.
- 3.2. The Care Act 2014 consolidated all previous legislations around carers, support services and social care into one overarching statute. The Act for the first time has made it a statutory duty requiring the council to asses all carers who request it. It has been described as the biggest change to the law in 60 years<sup>1</sup> and has brought new responsibilities for local authorities, and has major implications for adult social care and support providers, the people who use services and their carers.
- 3.3. Most of these new changes came into force in April 2015, amongst these the most important changes are the way in which local authorities should carry out carers assessments and needs assessments, and how local authorities should determine who is eligible for support.
- 3.4. The Health Scrutiny Panel as part of its work programme was keen to see how the Care Act had been implemented locally and specifically the duty in relation to unpaid carers. A scrutiny challenge session was held on Wednesday 13<sup>th</sup> May 2015 at the Tower Hamlets Carers Centre. The challenge session focused on a number of key questions:
  - What are the council's proposals for supporting carers in light of the new Care Act 2014?
  - How has the council supported service users previously, and is there going to be any reduction or access to services, and what new measures is the council proposing to put in place?
  - Is the carer's plan being refreshed or reviewed and how will it change in conjunction to the new regulations?
  - Which partners are providing carers services currently and will there be a new commissioning strategy for carers services in light of changes?
  - What feedback do we have from carers to understand how support services enable them to continue with their caring role, this should include details of things that work and areas for improvement?
  - How are carers engaged and involved in the design, delivery and scrutiny of services to carers?
  - What will the council and its partners do to raise the voice of the carers and ensure their involvement in the decision making process?
- 3.5. The Session was attended by the following stakeholders:

Cllr Asma Begum	Chair, Health Scrutiny Panel
Cllr David Edgar	Member of Health Scrutiny Panel

<sup>&</sup>lt;sup>1</sup> https://www.gov.uk/government/speeches/care-bill-becomes-care-act-2014

Lyn Middleton	Chief Executive, Tower Hamlets Carers Centre
Sharon Currie	Carers Forum Chair
Bill Gibbons	Services Manager, Alzheimer's Society Tower Hamlets
Frances McConville	Carer Support Worker, Alzheimer's Society Tower Hamlets
Luke Addams	Interim Director, Adult Services, LBTH
Dorne Kanareck	Interim Service Head, Commissioning and Health, LBTH
Tahir Alam	Strategy, Policy and Performance Officer, LBTH
Leo Nicholas	Senior Strategy, Policy and Performance Officer LBTH

# 4. Caring in Tower Hamlets

- 4.1. According to the 2011 census data there are 19,356 unpaid carers in Tower Hamlets which is 7.6% of Tower Hamlets resident population. Tower Hamlets has a higher proportion of younger residents than London and England who are providing care. Almost 39% of those providing care are aged 16 -34 compared to 21.4% in London and 14.1% in England. Approximately 29.4% of all carers are aged 35 49.
- 4.3. The highest proportion of hours of unpaid care provided is 1 19 (56.6%) hours, followed by 50 + hours (25.4%) and lastly 20 49 hours (18.1%). 42.9% of carers are Bangladeshi and 32.8 per cent are White British.
- 4.4. Around 56% of those providing care are female and 44% are male. This is slightly lower than the national and regional average. In London and England almost 58% of carers are women.
- 4.5. However, strikingly there is a higher proportion of the population providing 50 or more hours of unpaid care per week than any other place in England. Tower Hamlets also has a higher proportion of carers with bad or very bad health, almost 9% compared to 6.4% in London and 6.6% in England. Many carers provide care in difficult circumstances and they rely on the support that the council and local health and third sector providers offer to continue in their role caring role.

# 5. Carers Challenge Session

# 5.1. The New Local Carers Plan

Luke Addams, Interim Director for Adult Services and Dorne Kanereck, Service Head for Commissioning and Health reported that the council has refreshed the Carers Plan to meet the requirements of the changes brought in by the Care Act 2014. This is an initial one year plan which will change as the council better understands the implication of the Care Act locally and to meet the needs of carers more effectively.

- 5.2. The Carers Plan includes a focus on the following:
  - Early Intervention and support
  - Information and advice
  - Prevention
  - Urgent response

- Carer assessment
- Cared-for assessment
- Support planning and personal budgets
- 5.3. In developing the Plan the council engaged service users, service providers and other local organisations. The council also utilised information from the adult social care Pan Provider Forum, where a range of service providers meet to discuss issues around social care.
- 5.4. Lyn Middleton, Chief Executive of the Carers Centre highlighted that not all organisations that provide care services, including the Carers Centre, attend these meetings, as they have not found them useful in the past. She said that there has not been enough engagement from council services with organisations to learn from their experience delivering care services.
- 5.5. It was suggested that the council engage with organisations like the Carers Centre and Alzheimer's Society, as well as other organisations that provide services to carers, who have years of experience working intimately with carers and the cared for, in order to inform the new Plan. This should also include engagement of the Carers Forum and carers.
- 5.6. Bill Gibbons articulated that Alzheimer's Society have developed substantial expertise in the caring economy having delivered numerous contracts over the years. The council should look at the work that services such as the Alzheimer's Society have undertaken and to build upon good practice.
- 5.7. He cited an example where the Alzheimer's Society delivered training in schools to young people, as young people are both informal carers and also one of the first to recognise when someone in their household may need caring support. This is an example of a type of service that has not been considered at a broader level, especially one that could assist in identifying numbers of new and unaccounted for carers in the borough.
- 5.8. Additionally Lyn Middleton added that in thirty years of providing care services, many of the same issues are still prevalent, and she is uncertain whether the council has considered these prevailing issues. Therefore it would be useful for the council to spend time listening to organisations and their users, and the real lived experiences, stories and difficulties carers go through in their caring role to support the development of the new Carers Plan.

## Recommendation 1: That the Carers Plan be developed in partnership with local carer service providers, carers' forum and in consultation with local carers.

# 6. Assessing Carers

6.1. The council has designed a new approach to carers assessment that is similar to the way cared for people are assessed. The council has been working with organisations, primarily the Carers Centre, in order deliver this new assessment approach, which also means working jointly on combined, family or individual assessments.

- 6.2. Previously eligibility for social care services was determined by a banding structure known as the Fair Access to Care Services (FACS). This provided local authorities with a common framework for determining individuals' eligibility, which included assessment for carers and cared for. According to these guidelines, the needs of assessed individuals were split into one of four categories; *critical, severe, moderate* or *low,* according to the level of risk, or an individual's potential loss of independence. Eligibility varied across local authorities in terms of which of these groups are entitled to public support.
- 6.3. Tower Hamlets Council used the critical and severe needs thresholds to determine an individual's needs for services. However, this FACS method of assessment is now redundant, and new guidance now entitles carers and the people they care for to a right to an assessment irrespective their level of need.
- 6.4. As the new assessment approach only came into effect in April 2015, its efficacy is yet to be determined nationally. However, Tower Hamlets have developed strong processes of referrals, self-assessments and carers assessments along with their partners.
- 6.5. Tower Hamlets Carers Centre however have expressed that support must be timely, and said that self-assessments which have been referred to the council, have been taking too long to be addressed, and carers are left 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, or whether they should look for support elsewhere. Some cares have been waiting for more than three months.
- 6.6. Luke Addams said that this was not acceptable and delays of such lengthy periods should be reported to him, however he will look into the current systems.

#### **Recommendation 2:**

That carers assessments are completed in a timely manner to ensure carers are supported to continue in their caring role.

### 7. Assessments and Quality of Assessments

- 7.1. Self-Directed Assessments aim to allow carers to undertake their own assessment focusing on the outcomes, which will improve their quality of life. This could range from amenities and adjustment in their homes to make life easier as a carer, or it could be personal time to socialise, go on a course or do other things.
- 7.2. The new approach to assessment is now focused on outcomes rather than just service provision. Therefore, individuals, as the core decision maker, will be asked specifically on 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 cares to enrol on training courses, or signposting to the types of educational programmes carers are interested in.
- 7.3. It was highlighted that some people have been caring for so long, or caring has taken up the majority of their lives, that it is difficult for them to see what life there is outside of their caring responsibilities. Individuals therefore may find it difficult to decide on

what they could do with their spare time. It is therefore suggested that when completing self-directed assessment; assessors need to consider offering options and ideas to carers on self-development, or self-fulfilment.

- 7.4. However, this offer should not exceed realistic expectations and raise hopes of amenities that cannot be granted. In the past carers, after being assessed by council staff, have been promised services that were later declined, 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.
- 7.5. This then requires that the council to train 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 of carers.

#### **Recommendation 3:**

That the council's social care staff are trained to support carers effectively by being aware of various services available in the borough to support carers including information, advice and guidance. This should also include managing expectations of carers.

- 7.6. Another area of concern, in relation to assessments, was that council staff were not giving enough detailed feedback to carers, whether verbally or in writing, as to why they were not eligible for services. Carers were therefore not able to understand why their assessments had been declined for services, and insufficient and unclear feedback left carers confused. Also carers found it difficult to appeal or provide further information or evidence to substantiate their claims, due to the lack of sufficient and clear information they had been given.
- 7.7. It was suggested that when giving feedback to carers, council staff should make a concerted effort to make sure they provide substantive and clear feedback, explaining to carers why they are not eligible for services. Additionally staff should have an awareness of any other universal and preventative services that are available locally, and sign post carers to these services where appropriate.

### **Recommendation 4:**

That carers are provided clear and substantive feedback when they are not eligible for services and appropriately signposted to universal and preventative services they can access.

#### 8. Publications, Literature and Printed Information

- 8.1. Many carers felt that leaflets, guides and other published information about services for carers were hard to understand, and the information about services was not integrated. Carers would prefer access to centralised published information about services including booklets.
- 8.2. Many carers could not distinguish the difference between social services and health services, and so were at risk of falling through the system. Publications should have a description of the various services, and what they offer.
- 8.3. Additionally there was insufficient information on the range of services that were offered both by the council and organisations across the borough, which carers could

choose from. Information about specific services would help carers to make an informed decision on what services they could access and should apply for.

8.4. It is recommended that the council review the current material they have on the range of council and partner services, and ensure publications are easily accessible, easy to read, and provide succinct information to the range of services that are available, both from the council and local providers of carers services.

### **Recommendation 5:**

The range of carers services available are publicised on the internet. We will review our investment in those services in response to feedback from carers through the assessment process and ensure that any new provision is appropriately publicised and that carers and relevant organisations are made aware of such changes.

# 9. Manual Handling

- 9.1. One of the most significant issues that affects the health and wellbeing of carers is supporting the cared for to move around on a regular basis.
- 9.2. 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 their 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.
- 9.3. It was suggested that the council provide a manual-handling course for carers which could be rolled out through organisations that provide care services. Staff in provider organisations could be given a 'train the trainer' course. Organisations can than deliver the manual handling courses directly to their carers.
- 9.4. Dorne Kanareck said that this could be something that could be commissioned jointly through the CCG, and could also have the potential for saving the council and CCG money. People may be presenting themselves at GP services with health issues resulting from improper heavy lifting and bad manual handling. Through appropriate training and support for carers they will be able to continue with their caring roles which will save the Council and NHS money in the long run.

Recommendation 6: That the council in partnership with Tower Hamlets CCG develop a manual handling training course for local carers to prevent long term harm and injuries to carers.

# 10. Respite Care

10.1. Another area of concern for organisations that provide carers services is the way the council has commissioned respite care. They feel that the council processes on granting respite care services have not taken into consideration the complex needs of carers.

- 10.2. The Carer Centre citied an example where many carers are having to take time off from employment for emergency care of people they care for. Respite services have not been working as well they should be.
- 10.3. In response the council has identified bed availability within respite care provision as one of the major problems; there are insufficient places within the borough and the council do not have their own.
- 10.4. The council however have been looking at respite care services being delivered in people homes, where staff will be deployed to go into homes and look after the cared for in their own environment.
- 10.5. Dorne Kanareck said that this is an area that the council are giving consideration to and it may be that respite services might need to be considered on a more individual basis in order to understand the complexities of needs. The council recognises this area needs further developing.

Recommendation 7: That consultation and engagement be undertaken with carers to better understand need for respite services and ensure these are designed to meet local needs.

## 11. Health Scrutiny Panel – 9<sup>th</sup> September 2015

- 11.1 The Health Scrutiny Panel at its meeting welcomed the challenge session report but thought there were two key areas missing from this. Firstly, there are many carers who do not recognise themselves as a carer because they see it as a duty or are supporting their family or friend. This lack of recognition means they do not access appropriate support services which would enable them to continue with their caring role, maintain their health and wellbeing and allow them to pursue their social and leisure interests. It was also noted many of these carers are accessing primary health care services mainly for the cared for person and sometimes themselves. This is an opportunity for GPs and other health professionals to help identify and signpost carers to relevant support services. The Director of Public Health commented that at present GPs data set on recording of carers in Tower Hamlets was very low. It was also agreed that the council can do more work to help unidentified carers access relevant support services.
- 11.2 Sandra Moore (Tower Hamlets CCG) agreed that the CCG can look into this and see how they can increase recording of carers within GPs. She requested this report be sent to the CCG for consideration by their management board. It was therefore recommended that the Tower Hamlets CCG work with local GP practices to improve carer recognition and recording. Also the Council work with local social care providers to increase carers accessing support services.

#### **Recommendation 8**

That work is undertaken by primary health care service and the council to help carers that do not recognise their role as carer to better support them to enable them to continue with their caring role.

11.3 The Panel discussed in detail examples of how many carers were not aware of benefits they can access. The additional financial stress of caring role was also having

a detrimental impact on many carers and more work was needed to support carers access appropriate benefits. It was agreed that the Council works with local services to strengthen support available to carers to access benefits advice services.

#### **Recommendation 9**

That welfare benefit support to carers is strengthened to ensure carers are accessing all available benefits that they are entitled to and do not have additional financial stress.

#### 12. Conclusion

- 12.1. The Care Act 2014 came into force in April 2015 and brings in a range of changes for social care services. Further reform that will be brought in gradually and it is therefore still too early to assess how the implementation of the Act at a local level is working.
- 12.2. The refreshed Carers Plan is a live document and will take into consideration the complex changing needs of the local landscape, and commissioning will also be contracted according to these needs. The Carers Plan will be reviewed on a 6 monthly basis to consider any further changes and how it can be improved.
- 12.3. By engaging carers and organisations that provide care services, this report sets out a number of recommendations to assist the development of carers services in the borough.
- 12.4. The recommendations promote further partnership and collaborative working between the council and external stakeholders to inform the council's Carers Plan. It also recommends that the council roll out assessment training to its staff, which equips staff with a detailed understanding of information, advice and guidance around carers and the services that are available to carers.
- 12.5. This report also stresses the importance of having publication materials that offer easy to read clear guidance and information on services that are available to carers across the borough. It also recommends that the council carefully reassess its respite care services to consider the complex needs of carers, possibly on an individual basis.
- 12.6 The Health Scrutiny Panel at its meeting on 9<sup>th</sup> September 2015 added 2 additional recommendations which improve identifying hidden carers and strengthen access to appropriate benefits for carers and thereby reducing financial stress for carers.