

# The Hidden Needs of Carers **in** Newham



June 2020

# Table of Contents

EXECUTIVE SUMMARY .....	3
ACKNOWLEDGEMENTS .....	4
INTRODUCTION .....	5
BACKGROUND .....	5
The National Context .....	5
Policy at National Level .....	6
Policy at Local level .....	6
The role of caring on health and wellbeing .....	7
Support for carers available in Newham .....	8
METHODOLOGY .....	9
Data Collection .....	9
FINDINGS .....	10
Caring responsibilities .....	10
Carer’s assessment .....	11
During the carer’s assessment .....	11
Support for carers .....	12
Challenges experienced accessing services as carers .....	14
Impact of being a carer .....	15
CONCLUSIONS .....	17
RECOMMENDATIONS .....	17
APPENDICES .....	19
Appendix I – Online questionnaire for carers .....	19
Appendix II – Structured interview questions for individual interviews .....	27
REFERENCES .....	29

## EXECUTIVE SUMMARY

Between October 2019 and February 2020, Healthwatch Newham engaged with 57 carers using a combination of online questionnaires, interviews, and focus groups.

### Key findings

#### Access to Carer's assessment

- 60% of carers had a carer's assessment. In contrast, 40% either did not receive a carer's assessment and if they did, they did not receive a follow-up from services. Barriers in arranging a carer's assessment included lack of response from the Adult and Social Care team or being denied the assessment.
- During interviews and focus groups, 26% of carers confused the carer's assessment with the need's assessment.

#### Support for carers

- Most carer's who attend peer support groups thought that it is the best place to find out current information for themselves and the people they care for. Some mentioned that the carer's assessment did not provide most of the information they learned by attending such groups.
- 14% of carers revealed during interviews that they do not have an emergency plan in place for the person they look after. Carers find this topic difficult to talk about.

#### Accessing health and social care services

- Most carers had a good experience of accessing primary care services, especially when provided by an attentive health care professional.
- Some carers complained that doctors do not involve them in the care of the person they look after.
- Many parent carers reported staff do not use hospital passports for patients with communication difficulties.

### Recommendations

1. GPs and social workers need to continue to identify carers to refer for the carer's assessment.
2. Carer's assessment must ensure (a) carers receive a copy of the assessment, (b) understand the difference between the carer's and the needs assessment, and (c) receive a follow-up.
3. Services are advised to provide information to carers in writing.
4. Services should increase awareness of mental health services available for carers.
5. Engage with a wide range of carers by partnering with local community groups or Healthwatch Newham.
6. Involve older carers in the development of strategic plans for longer-term plans.
7. Hospital passports should be used by ward staff at NUH and be included in staff training to promote awareness.
8. Services should continue to support carers' peer support groups with updated information and resources.

## ACKNOWLEDGEMENTS

Healthwatch Newham would like to acknowledge all those who have contributed to this project. To whom we thank:

- Healthwatch Newham's team of staff and volunteers who dedicated their time to this project.
- All community organisations and carers groups who partnered with us to run focus groups and engagement events.
- All the carers who took part in the online questionnaires and face to face interviews.
- The Adult and Social Care team who supported us with vital information about services.

### Healthwatch DISCLAIMER:

This report is representative only of the views of the carers who took part in this research between 2019 and 2020.

## INTRODUCTION

**Healthwatch Newham is part of a national network led by Healthwatch England, which was established through the Health and Social Care Act in 2012, to give service users of health and social care services a powerful voice both locally and nationally. We are the independent voice for people's views on Newham services, both good and bad. We listen to local people and feedback patient experience and liaise with local commissioners and decision makers, in order to improve services.**

In the last year, through various pieces of engagement Healthwatch Newham observed a pattern of issues experienced by unpaid carers in the local area. Most carers reported difficulties with accessing health services with the person they care for and not being recognised and valued as carers by health and social care professionals. In July 2019, Healthwatch Newham conducted an initial focus group with a peer support group for older parent carers to understand the main issues. Based on that information gathered from that focus group, the project expanded into investigating the experiences of carers in Newham. The aim was to explore carers' experiences of receiving a carer's assessment, their knowledge of and ability to access available support in Newham and the impact the role of caring has on their lives.

### What is a carer?

A carer is an individual who supports a family member, friend or partner who is ill, frail, disabled or has mental health or substance misuse problems<sup>1</sup>. Carers can be both children and adults, but for the context of this report. All participants were adults typically unpaid. Such carers usually help with personal care, help the individual access services, assist with physical care, and offer regular supervision to keep the person safe among many other types of support.

## BACKGROUND

### The National Context

According to the 2011 Census<sup>2</sup> data, there are 5.8 million unpaid carers in England and Wales, showing an increase of 600,000 unpaid carers from the previous census in 2001. These numbers are predicted to double over the next couple of years. In total, 24,604 of those carers reside in the London Borough of Newham (LBN), of which 21% provide 50 or more hours a week of unpaid care<sup>2</sup>. The increase in caring is likely due to a combination of greater life expectancy and more chronic and complex health conditions in the population.

---

<sup>1</sup> [Who is considered a carer? NHS England](#)

<sup>2</sup> [2011 Census Analysis: Unpaid Care in England and Wales, 2011 and comparison with 2001](#)

## Policy at National Level

According to the Care Act 2014<sup>3</sup>, local authorities (health and social care professionals) must provide carers with information on the services available and how to best access it. This information should cover a wide range of services and include how to obtain a carer's assessment.

## Policy at Local level

### Newham CCG and LBN Joint Carers Strategy 2015-2018

Newham CCG and LBN co-produced their 2015-2018 Joint Carers' Strategy with local carers, which establishes 5 outcomes: (1) Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role; (2) Carers will be able to have a life of their own alongside their caring role; (3) Carers will be supported so that they are not forced into financial hardship by their caring role; (4) Carers will be supported to stay mentally and physically well, treated with dignity and lastly, (5) Children and young people will be protected from inappropriate caring roles and have the support they need to enjoy positive childhoods. To achieve this, both partners established a few goals for the next couple of years. In summary, these include:

- Investing in on-going training of “*carers awareness*” for the staff team including social workers, healthcare professionals, mental health team and third sector workers on how to identify carers and those at risk.
- Improve carers' access to education, employment and training opportunities (e.g. safeguarding, medicine management, etc.). In addition to increasing awareness of working carers with local employers and inform carers of their employment rights.
- Ensure information regarding carers and how to access support is available at different levels and formats.
- Improve the carers' assessment process by reducing the time it takes but also by taking a whole family approach to offer individualised support.
- Improve access to wellbeing activities (e.g. cooking classes), volunteering, preventive and self-care management support (e.g. therapy, peer support groups, etc.).
- Encourage carers to use flexible health services (e.g. online or double GP appointments).
- Develop better working relationships with other partners including mental health services, primary care, third sector and others to better support carers in their role.

### Receiving a Carers Assessment

Anyone who cares for another person is eligible for a carer's assessment in which, information, advice and guidance will be provided to support the carer's needs. It should always be free of charge and conducted by a social care officer. The assessment touches on a variety of topics including: sustainability of care, ability to care for another adult, nutrition habits, management of the family home and relationships, work and education, access to community and leisure facilities, and lastly the impact on the carer's physical and mental

---

<sup>3</sup> [Care Act 2014 Online access](#)

health. In Newham, the carer's assessment is often combined with the Needs Assessment for the person-cared-for.

#### East London NHS Foundation Trust (ELFT) Carer Strategy 2017-2019

The ELFT published this strategy based on feedback from local carers. ELFT is responsible for providing mental and community health services in East London, including Newham. The strategy sets 5 key aims: (1) to identify and recognise carers, (2) communicate with and involve carers, (3) provide information for carers, (4) facilitate access to support for carers and (5) work in partnership with the local authority.

For *Aim (1) identify and recognise carers*, the Trust reminds staff of the importance of identification of carers via emails and during team meetings. It also uses posters to remind staff that carers may identify in different ways (e.g. as mothers, friend, partner, etc.). The Trust plans to pilot a family intervention carers group within the Early Intervention Service, carry on their QI projects and make a review of all carers in their network to send more information. For *Aim (2) communicating with carers and involving them*, EFLT currently encourages carers to take part in the care of the person they care for: Carers are regularly invited to attend CPAs<sup>4</sup>, medical review meetings and join psychology sessions with the service users; carers are represented in the Working Together Groups and take part in numerous QI projects. In addition, staff in various services are often reminded of the important role carers have in the recovery of their patients. With this strategy, the ELFT team intends to set a regular carers' focus groups, develop a carers' pack, allow carers to produce their own newsletter for the network and review their list of carers to refer for carers' assessments and extra support. For *Aim (3) provide information for carers*, the EFLT services already provide carers with general information including on medication, its side effects, etc. (leaflets available in all wards). This information is also available to staff. For the next couple of years, EFLT plans to review their leaflets and ensure they are up to standard and optimise their availability. For *Aim (4) facilitate access to support for carers themselves*, leaflets with information regarding support for carers are available in all wards and the MHCOP<sup>5</sup> offers psychological support for carers (including individual therapy, advice sessions and groups). ELFT plans to continue to foster these relationships and support pathways. Lastly, for *Aim (5) work in partnership with the local authority*, ELFT states that there is already an on-going relationship established between ELFT, their carer support team and the London Borough of Newham. The plan is to continue developing these relationships with the local authority.

#### The effect of caring on health and wellbeing

The amount of care one provides is associated with poor health<sup>6</sup>, therefore carers providing 50 or more hours of care a week tend to have poorer health when compared to their non-carer counterparts of the same age. Within London, the east inner boroughs show more

---

<sup>4</sup> Care Programme Approach (CPA) meeting is used to discuss service user's care plan in mental health services.

<sup>5</sup> Mental Health Care of Older People (MHCOP)

<sup>6</sup> This is a correlation, it does not mean caring for someone directly causes poor health, but it is likely to influence it.

carers with reported poor health: Newham with 2,909 carers with poor health (of which 1,144 or 39% care for 50 or more hours weekly), followed by Tower Hamlets with 2,496 and Hackney with 2,270<sup>7</sup>. In general, these statistics suggest that the local authorities with the highest level of disabilities and illnesses are more likely to have carers with poorer health<sup>8</sup>.

### [Support for carers available in Newham](#)

Besides the usual nationwide financial benefits (e.g. Carers allowance, attendance allowance, PIP, etc.), Newham has a few services that provide extra support to carers:

#### Carers Services

LBN has commissioned [CarersFIRST](#) as the integrated care support service across the borough. They provide information, advice, training opportunities and emotional support to carers both in person at community centres/libraries but also online. The previous commissioned service, [Carers Empowerment Programme](#), still delivers training and workshops for carers (e.g. welfare benefits, first aid, etc.) at the time of writing this report. Free online training is also available through Newham libraries (Inc. end of life care, wellness coaching, caring for seniors, etc.)<sup>9</sup>.

#### Carers Emergency card scheme

This scheme allows carers to prepare alternative support arrangements for the person that they care for. To be used when they are not able to carry out their caring responsibilities due to an emergency.

#### Carer involvement

If carers wish to advocate for issues they and their community face, they are encouraged to join patient participation groups including the Working Together Groups, which are run by ELFT and are a platform for residents and patients to discuss issues that matter to them and their communities<sup>10</sup>.

---

<sup>7</sup> [In Poor Health: The impact of caring on health. CARERSUK 2004](#)

<sup>8</sup> [Disability in England and Wales: 2011 and comparison with 2001. Office for National Statistics](#)

<sup>9</sup> [Online training opportunities via Newham libraries](#)

<sup>10</sup> [Working Together Groups, ELFT](#)



## METHODOLOGY

To explore the experiences of carers in accessing health services and receiving support, as well as the impact caring has on their lives, Healthwatch Newham used a mixed-methods approach. Carers were asked to either complete an online questionnaire, take part in an interview or a focus group. The qualitative data from the interviews and focus groups were analysed using a thematic analysis technique (Braun & Clarke, 2012), which seeks patterns or themes within the data. This project explored three main themes:

- What are carers' experiences of the carer's assessment?
- What are carers' experiences of accessing health and social care services?
- What impact does caring have on carers' lives?

### Materials

A questionnaire was co-produced with carers to include questions they deemed important and collect both quantitative and qualitative data (Appendix I). A very similar questionnaire (Appendix II) was developed for the semi-structured interviews and focus groups. The interviews and focus groups served as opportunities to gather richer data and to offer carers a chance to discuss the topics further.

### Data Collection

All opportunities were advertised online (Email networks, social media, newsletter, etc.) but also via word of mouth to reach those with limited access to computers. To reach more vulnerable individuals, the team organised 3 focus groups with local peer support groups for carers. One of the focus groups was aimed at individuals who did not speak English fluently, therefore an interpreter was used. Questionnaires took an average of 6 minutes to complete and interviews were on average 90 minutes long. Data collection took place between October 2019 and February 2020, apart from one focus group which took place in July 2019.

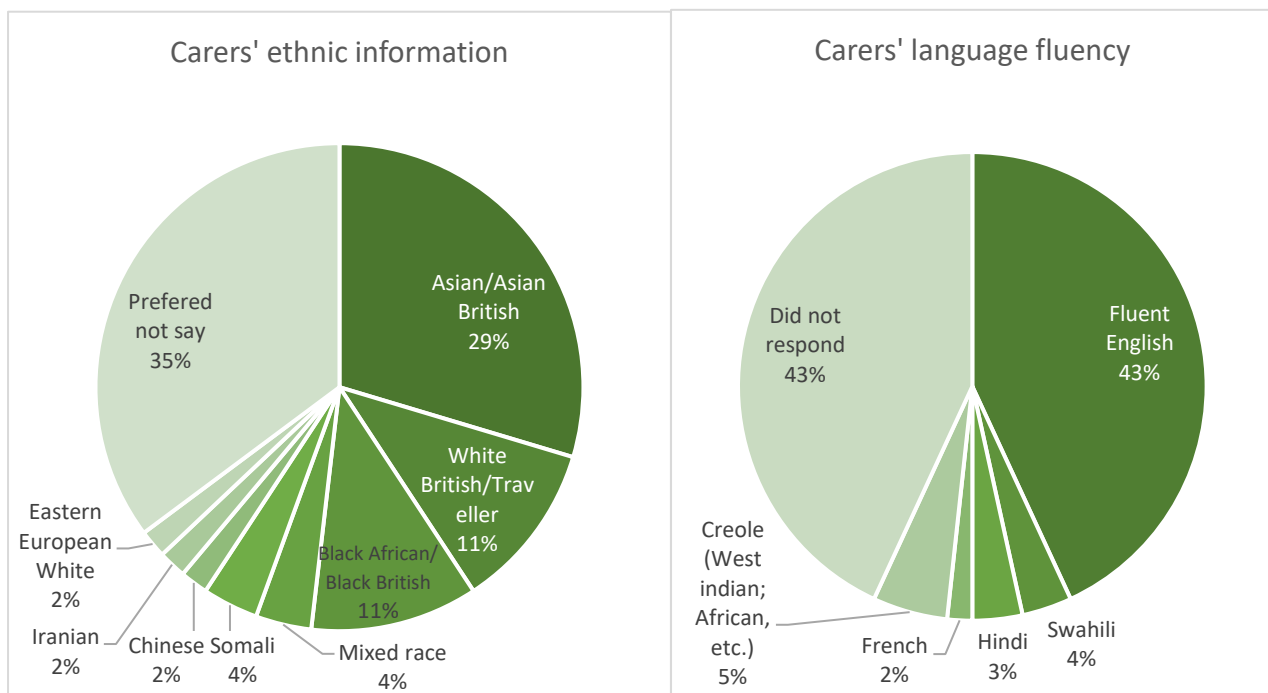
## FINDINGS

### Demographics of the carers

- This project engaged with a total of 57 carers: 9 took part in the interviews, 23 completed the online questionnaires and 25 took part in 1 of the 3 focus groups.
- In total, 7 (12%) identified as men, 31 (54%) as women. The remaining did not respond.
- Age ranged from 31 to 71 years old, with the average being 46 to 60 years old (32%). Only half of the carers (56%) provided information about their age.
- Although the sample is very diverse, 43% of carers speak fluent English at home (see Graph 1 and 2.). Also, ethnic background did not influence carers' experiences.

### Caring responsibilities

- 53 carers (93%) look after a family member, most commonly their adult children and/or spouses. 2 (3%) look after a family friend.
- On an average week: 19 carers (33%) provide full-time care, 6 (11%) provide more than 24 hours, 3 (5%) carers offer 2 to 12 hours, another 3 (5%) offer less than 1 hour and 1 (2%) carer provide 13 to 24 hours. The remaining 25 (44%) carers did not answer this question.
- Of the 27 participants who responded, 16 (28%) were unemployed and caring full-time, 6 (11%) had part-time jobs, 3 (5%) were retired and 1 (2%) was in full-time employment. Bear in mind that although unemployed, many of the carers who took part in this project voluntarily run or support with the setting up of peer support groups for other carers.



Graph 1. Sample ethnic information.

Graph 2. Sample language fluency.

## Carer's assessment

- In total 34 carers (60%) said they received a carer's assessment, of which only 9 of those (26%) received a follow-up. In contrast, 23 carers (40%) either did not receive a carer's assessment or if they did, they did not receive a follow-up or a copy of the report afterwards.
- Some of the 23 carers revealed they faced some barriers in booking a carer's assessment: 3 carers revealed difficulties in establishing contact with the Adult Social Care team. They mentioned that services took a long time to respond or at times did not respond to communications at all. 4 carers of the 23 (7%) reported that they were denied the carer's assessment upon their request. Carers explained that staff told them they do not qualify for an assessment because the person they looked after was not "sick" enough. In addition, 1 carer did not know about their entitlement to a carer's assessment:

*"I have tried getting a carers assessment done. I've called the social care services, but they don't respond to my emails."*

*"I was told that I don't qualify to get carers assessment"*

*"Not gone through the carer's assessment. I have asked for a carer's assessment, but they wouldn't do it. They [adult social work team] responded negatively... that it was somehow my fault that my children are this weak"*

*"I did not register as a carer in the social services because we live in different boroughs. He [the person being cared for] has to live in the same borough as me, right?"*

- During interviews and in 1 of the focus groups, 15 carers (26%) were confused between the carer's assessment and the needs assessment for the person they care for. This resulted in unrealistic expectations of what they could receive from a carer's assessment.

*"I am not sure if that was the carers assessment"*

*"They [carers' assessment] focus on personal care activities. [...] Some people may be able to brush their teeth, brush their hair but still have difficulties..."*

## During the carer's assessment

We asked carers to share their experiences of the carer's assessment process.

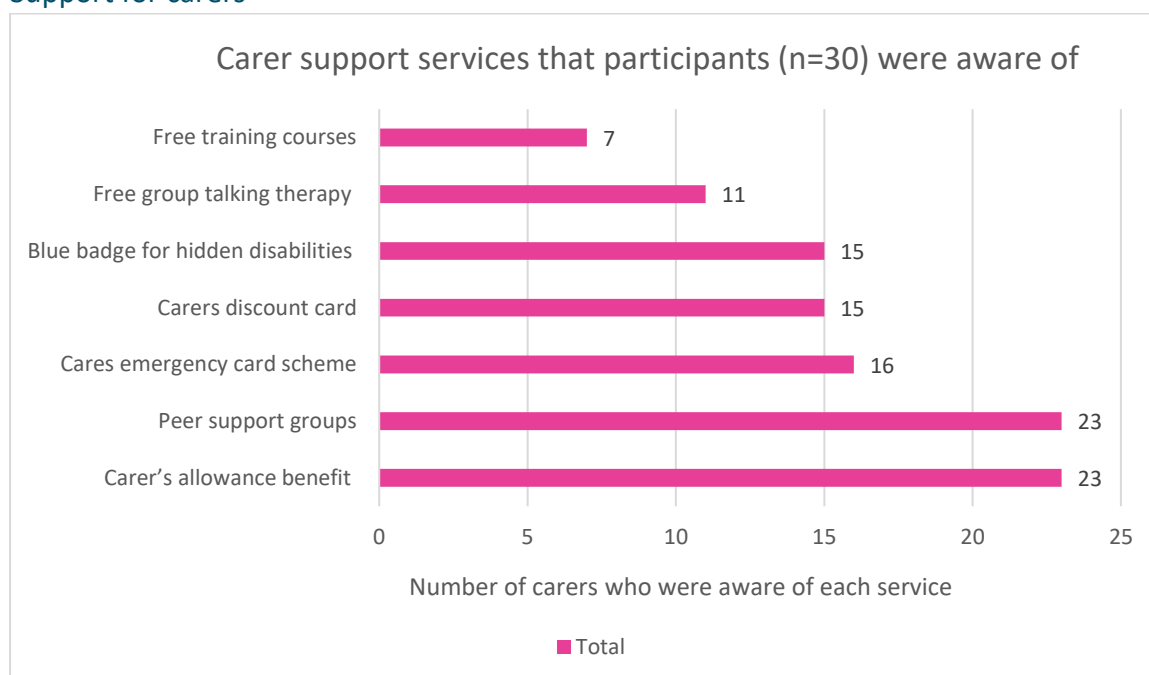
- From the 34 that had a carer's assessment, 7 carers (21%) received further support after the assessment. 6 carers (18%) said they did not receive any further support. *Only 13 answered this question.* Of those who specified, the further support included carer's discount card, respite support and support with personal budgeting.
- 6 carers shared feedback on what went well during the carer's assessment: 4 carers said it was a good system to identify their own needs, 1 mentioned that it provided clarification on the services available for carers, and 1 said that the staff were "patient and pleasant".
- In contrast, carers reported that there are a few points that can improve the carer's assessment process: 1 carer found that the social worker did not share important

information during the carer's assessment, such as their entitlement to a double appointment at the GP for their disabled child. 25 carers (44%), including those from two of the focus groups, suggested that the carer's assessment should incorporate a mental health support component.

*"They [social services] never followed it up, they suggested lots of things but did not come back to me."*

*"They also don't take into consideration carers that have disabilities or mental health issues themselves. They say if you care for someone you cannot be mentally unwell yourself... But that's my son! I am not going to stop caring for him"*

### Support for carers



Graph 3. List of services carers in this report are aware of. A total of 30 carers answered this question

Newham has a range of free support services available for carers. Carers may not use all services, but it is important to know whether carers are aware of such services so that they can decide to take advantage of them when needed. All carers except those in the focus groups were shown a list of available services in Newham for carers and asked if they were aware of them. A total of 30 people (53%) answered this question (21 from online questionnaires and 9 from interviews). The results are noted in Graph 3 above. Most carers were aware of the carer's allowance benefit and the peer support groups. Fewer carers seemed to know about the free training courses and group talking therapy available in the borough.

When asked, out of the 23 carers who were aware of peer support groups, only 15 attend such groups. 3 of those carers said that they either run or supported their own peer support group in the community. The other 12 stated that it was useful to attend because it was the best way to find out about services and sources of support available for them, but that it also served as an opportunity to socialise with others who understand their difficulties. A few

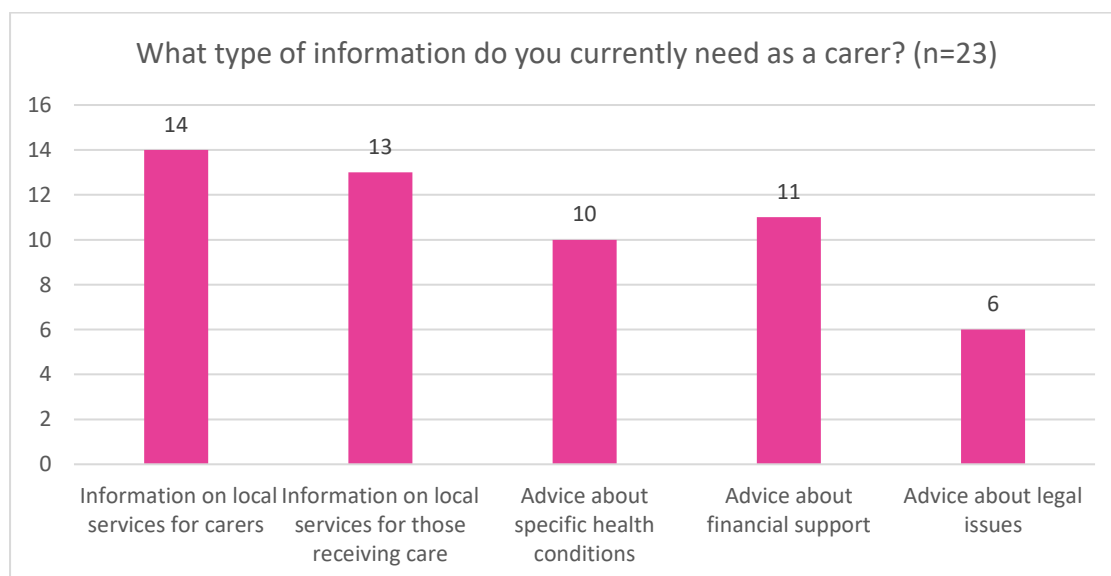
carers mentioned that peer support groups were more effective in sharing information on services and support available for carers than the carer's assessment. Reasons for not attending peer support groups were due to lack of time, energy or not being able to leave the house.

*"I know of peer support groups, but I don't attend because what is the point... Yes, they do talk and socialise, but also I do not have the time. I am always exhausted from my caring duties."*

*"I feel that there is a lot of information out there that many carers are not aware of, that is why I volunteer my time to help other carers and help fight their cases."*

Further feedback from the interviews and focus groups revealed that 6 carers (11%) were not aware they could request a double GP appointment for the person they care for. Also, 8 carers (14%) said they had been advised by social services during their carer's assessment to think of what emergency plan they wanted for the person they care for. During the assessment Social services only provided one option, consisting of placing their adult children or spouses in a care home, which none of the carers liked. None of the 8 carers had an emergency plan in place yet by the time of the interviews. Although carers were willing to discuss emergency plans, they found it difficult to think about this topic and did not trust anybody else or other services to look after their loved ones.

When asked about longer-term plans in one of the focus groups, carers agreed that they did not like the option of the care home or supported living. This was because social services would not provide an option of gradual introduction of the cared-for person, so that so that the person could get used to the new environment over time and then move into it permanently when needed. Also, if families were not happy with the allocated care home during the trial period, social services would not be flexible enough to provide other care homes to trial.



Graph 4. Most common information carers in this report stated they need. A total of 23 carers answered this question.

Carers who completed the online questionnaire (n=23) were also asked what type of information or advice they currently need and would find most helpful. Responses are shown in Graph 4 above. Carers are more concerned with services targeted at them and the people they care for. This is generally the type of information that is shared with carers during a carer's assessment. Carers also suggested having one point of access for all carers such as a physical hub, where they can receive information and emotional support.

#### Accessing health services as carers

When asked about their experiences of accessing health services (e.g. GP, dentist, hospital, etc.) with the people they care for, 4 key themes emerged:

- (1) **Good or average experience.** The majority who answered this question revealed either a good or average experience of going to the GP or hospital. Their experiences were more positive when carers were seen by attentive and caring healthcare professionals.
- (2) **Issues with availability of appointments.** 3 people experienced issues related to lack of appointments and long waiting lists. In one of the focus groups, carers thought they had to 'register' with a dentist and did not know they could attend any practice for check-ups or treatment.
- (3) **Communication during appointments.** 2 people who care for adults with autism and dementia shared that their difficulties were around healthcare professionals not allowing carers to speak on behalf of the patient they care for. One carer explained:

*"The problem is that they [the doctors] don't involve me in the appointments even if my [adult] son say that he wants me there. (...) my kid cannot communicate in that way [being clear and ask for what he wants]. I have to advocate for him, so if they don't allow me in these appointments then my kid is not getting the help he needs."*

- (4) **Lack of support during inpatient hospital admissions.** Carers, especially those in focus groups and interviews, reported facing difficulties when the person they care for is admitted to hospital for a night or longer. This was particularly difficult for carers of people with very complex needs (e.g. cerebral palsy) who usually benefit from a couple of hours of paid carers to support with handling, lifting and personal hygiene. When the person being cared for is admitted to hospital, the paid carers are not allowed to continue providing the care as it is assumed that nurses will offer the necessary care whilst on the ward. However, parent carers report that most times nurses do not have the capacity to provide this support. As one carer recalled...

*"It is difficult. When we take him to hospital and he has to stay the night, the paid carers are not allowed inside as the regulation states that the nurses in the ward should be doing the carers job and therefore the council won't pay for double service."*

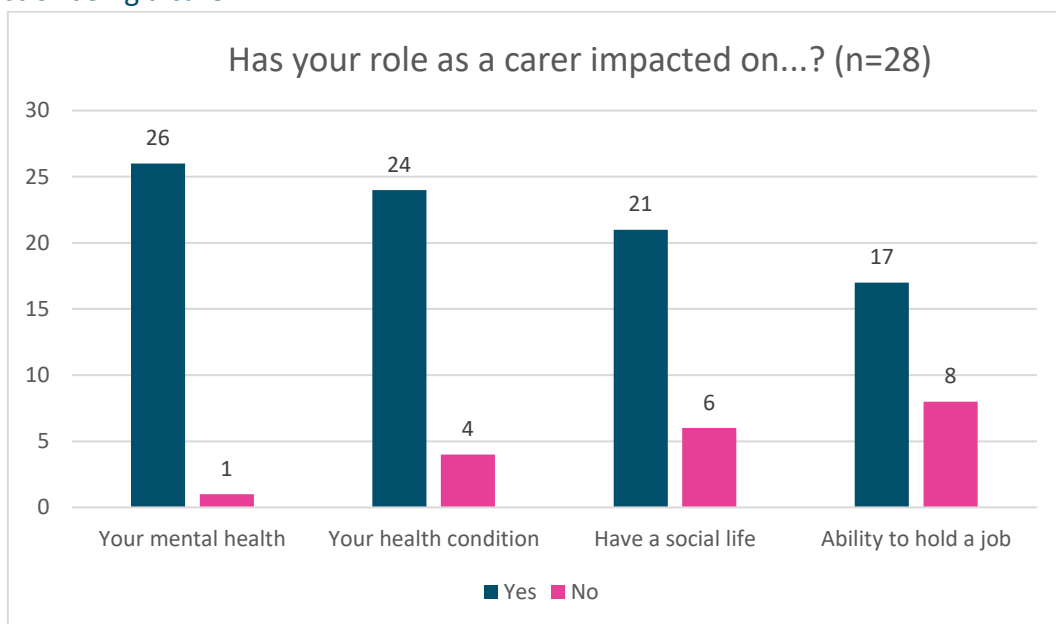
The responsibility then falls on the parent carers. It is important to note that individuals with complex needs often need help to feed and take care of their general hygiene. Some parent carers have physical disabilities of their own, making such tasks very difficult,

especially if carers have other children at home. Carers who look after individuals with cognitive or mental health conditions, such as autism or learning disabilities, also reported that their adult children’s hospital passport is rarely used. This was not the case when the child did not suffer from a cognitive or mental health conditions.

*“The hospital records do not seem to show that some patients have learning disabilities or autism, or where it is recorded, staff do not check the records and put appropriate care in place. The Healthcare Passport is not used or recognised. The process works better in London Hospital than in Newham University Hospital.”*

(5) **Quality of supported living and day centres for adults with learning disabilities.** In one of the focus groups, participants discussed in detail their concerns of supported living services. Parent carers mentioned their adult children often would return home from the day centre more upset than when they had left the house. Some parents mentioned issues with paid carers at such institutions including: (a) wrong allocation of medication on wrong days, (b) lack of communication with the service user (e.g. explaining what medication they are giving, etc.), (c) the quality of support workers varies greatly.

#### Impact of being a carer



Graph 5. Impact of being a carer

According to carers, the role of caring for someone has a strong impact on their mental and physical health. All 28 carers who completed this set of questions, reported the impact was negative. A common theme amongst carers was stress and anxiety, from being worried about the people they care for but also due to having to “constantly fight” for support. This in turn has implications on their physical health. In fact, some of the carers were disabled themselves as stated previously. Many carers shared that it was difficult to maintain a social life. This was because the person they cared for was difficult to manage in social settings, or because carers were too exhausted from daily caring activities, therefore opting to avoid social gatherings.

*"I can't have a social life, no time at all. I can't even dream of a social life. I would like to be able to go out and have friends but that is just not possible. The truth is there is not 2 of me to look after my children."*

Only 7 (13%) carers were employed and only 1 of those was in full-time employment, with the remaining working part-time. Some carers had to give up their jobs to have enough time to provide care. 2 full-time carers mentioned that to make ends meet they worked on freelance basis providing advocacy and consultancy of welfare benefits to others in need. The main barrier to hold full-time jobs was the need for flexible working hours so that carers could attend to the needs of the person they care for at any given moment. This was true even for carers who had the support of paid agency carers for a couple of hours a day at home, as the example below state:

*"Even though my son has this support [paid carers], I still have to be there in the house when the carer is there. Sometimes I can go out but need to be ready to return at any moment if the paid carer calls me asking for support. That is why I don't feel comfortable taking on a job even if part-time if then I will not be able to go to my son's assistance."*

### Case study – MJ

MJ is a 50-year-old single mother who cares full-time for her 25-year-old and 18-year-old children. They have learning disabilities, autism, and epilepsy. For MJ being a carer has taken a toll on her mental health and wellbeing, especially over the last few years. She found caring for her children more manageable when they were younger - the children had a strict routine and would spend most of the day in school and at extra-curricular activities. During this period, MJ even learned how to drive and took part in a few community groups during school hours.

Once her children graduated from college and faced adulthood, it became more difficult. With no school to attend during the day, the lack of support from social services and family support, MJ saw herself spending 24/7 with her children with no breaks. She wishes for her children to lead an independent life and possibly take on a job. However, their chances of employment are limited due to their intellectual ability. MJ thinks that the local council should try to offer employment advice and support to disabled adults so that they can be motivated to lead an independent life as much as possible. Because the children do not have any other source of support and find it difficult to go to different environments, MJ feels restricted in what she can do. To MJ, her life is not her life. She feels that she cannot manage romantic and friendly relationships, does not have the time or energy to do things she enjoys or take on a job. She often feels emotionally and physically drained. MJ wants more than anything, for social services staff to understand the impact caring has on people like her.



When asked, 16 carers (28%) revealed they actively try to take time out to rest and partake in an activity they enjoy. Some of the activities included socialising such as attending peer support groups or taking part in exercising such as yoga, swimming, and outdoor walking.

## CONCLUSIONS

- Most carers receive the carer’s assessment; however, some still experience difficulties in receiving follow ups and getting in contact with the Adult Social Care team.
- It is important to note that the Adult and Social Care Newham team often conducts the needs assessment and the carer’s assessment combined into one session. The distinction between the two assessments is not always explained to clients, therefore leading to confusion at times.
- Peer support groups for carers should not be underestimated. Such groups serve as a platform for many carers to feel connected to their communities, receive social support and stay updated on services and support available to them and the person they care for.
- Establishing adequate emergency plans for carers has been an ongoing issue for the Adult and Social Care team. This will be one of the focuses for the new Joint Carer’s Strategy being developed in 2020.
- Healthcare staff’s attitudes has a big impact on the experiences of accessing both primary and secondary care services.
- Being a carer affects most aspects of someone’s life, in particular mental and physical wellbeing. It can also be hard to keep a job, even if part-time.

## RECOMMENDATIONS

Recommendation	Recommendation for
1. Although most carers had the carer’s assessment, some still face difficulties as some are not identified as unpaid carers. Adult Social Care and GPs should review their processes to be able to identify all carers at first point of contact and refer them for a carer’s assessment.	Adult Social Care, CCG/PCCC
2. Social care services should ensure that all those who receive a carer’s assessment: (a) receive a copy of their assessment, (b) are clear about its content including the distinction between carer’s assessment and needs assessment for the person they care for and (c) receive a follow up at a later date to confirm they received the required support.	Adult Social Care
3. Often carers forget or misunderstand the information shared by social workers during a carer’s assessment, therefore, services are advised to provide information to carers in writing.	Adult Social Care

<p>4. Although the carer's assessment enquires about mental health, many carers were unaware of mental health support available to carers in the local area. Services should ensure all carers are aware of the sources of support available during the carer's assessments but also by sharing information online, via peer support groups and community events.</p>	<p>Adult Social Care</p>
<p>5. Services should think more creatively about how to engage with carers from a range of backgrounds (e.g. Non-English speakers, older carers, disabled carers, etc.). Services can collaborate with community groups and Healthwatch Newham to ensure a wide range of voices are heard, including those that do not access services frequently.</p>	<p>Adult Social Care</p>
<p>6 Older carers of adults with learning disability told us they had concerns about the long term plans for the people they care for and found it difficult to develop a long term plan for when they are no longer there. Social Services can address this by: (a) Engaging with older carers in the development of the strategic plan, to ensure their voices are heard during the planning process. (b) Look at the current long term planning offer and identify gaps, for instance older cares told us that they wanted the person they care for to find a suitable home where they could move into when the time comes and be given the time to acclimatize to the new environment.</p>	<p>Adult Social Care</p>
<p>7 The hospital passport should be used by ward staff to quickly 'get to know' the patient and make the necessary adjustments are made and are included in staff training to promote awareness.</p>	<p>Barts NHS Trust</p>
<p>8 Social Care Services should continue to promote and encourage cares to attend carers' peer support groups and provide relevant information related to events, support available, updates about services (e.g. flyers, booklets), and promotional materials, especially in other community languages. These groups are an important source of support for many carers, including those who do not often access services.</p>	<p>Newham carers strategy group</p>

# APPENDICES

## Appendix I – Online questionnaire for carers

---

### 1. Welcome!

You are being invited to take part in a Healthwatch Newham project which focuses on exploring the needs and experiences of carers who live in the local area. We will ask a few questions about your caring duties, the support you receive as well as the difficulties you face to do your role.

This will take 15 minutes to complete.

All information collected is anonymous. The data will be used for a general analysis and a report will be written and shared across Newham's healthcare boards with relevant recommendations to improve support for all carers.

Do I have to take part?

It is up to you to decide whether to take part. If you later decide you want your data to be excluded from this research, please email the Healthwatch Newham team with your unique participant code.

Contact information:

[Info@healthwatchnewham.co.uk](mailto:Info@healthwatchnewham.co.uk)

020 3866 2969

1. Create a memorable word/number as your unique ID number

## 2. Introduction

\* 2. Who do you provide care for?

- A friend
- A family member
- A neighbour
- I do not care for anyone
- Other (please specify)

3. How many hours roughly a week do you spend caring?

- Less than 1-hour weekly
- 2-12 hours weekly
- 13-24 hours weekly
- More than 24 hours weekly
- Full time carer

4. Are you officially known to the **Adult Social Care** team as a carer?

- Yes
- No

5. Are you officially known to the **GP** as a carer?

- Yes
- No

6. How did you register yourself in the system as a carer?

7. Have you heard of the Joint Carers' Strategy written by Newham's Clinical Commission Group?

- Yes
- No

### 3. Carer's Assessment

8. Have you taken part in a carer's assessment?

- Yes
- No

Tell us more about that experience:

*(E.g. did they ask about all relevant aspects of your life? Did you discuss your mental health? Did you like the experience? Was it useful? How did it benefit you and your caring duties? etc.)*

9. What went well?

10. What did not go well?

11. What could have gone better?

12. Did you receive the final report of your assessment to see whether you agree with it or not?

- Yes
- No

#### 4. Support for carers

13. Did you receive support after the carer's assessment?

Yes

No

14. If so, what services/support did you receive?

15. What was good about the support you received?

16. What type of support was missing in your opinion? What other service or support do you feel you still need?

17. What type of **INFORMATION** do you **CURRENTLY NEED** most as a carer in Newham?

Information on local services for carers

Information on local services for those receiving care

Advice about specific health conditions

Advice about financial support

Advice about legal issues

Other (please specify)

18. Do you **KNOW ABOUT** the following sources of support available for carers in Newham?

- Carers' Allowance benefit
- Free training courses including budgeting, safeguarding, managing long term conditions and others
- Carers' Emergency card scheme (make arrangements for the person you care for in case you are in an emergency)
- Carers' Discount card
- Peer support groups for carers
- Newham free group therapy workshops (Newham Talking Therapies service)
- Blue badge for Hidden disabilities
- I don't know about any of the above

19. Do you attend a peer support group for carers?

- No
- If yes, is it useful?

20. Have you heard of the self-management programme in Newham pharmacies?

- No
- If yes, have you used it? How did you find it?

21. How is the experience of accessing health services with the person you care for (e.g. GPs, Health checks, mental health services, etc.)?

## 5. Impact of caring for someone

22. Are you in paid employment?

- No
- If yes, how is the experience of having a job alongside caring?

23. Has the role of caring negatively impacted your own health condition?

Not really                      More or less                      Yes, it has                      N/A



24. Has the role of caring impacted on your ability to hold on a job?

Not really                      More or less                      Yes, it has                      N/A



25. Has the role of caring impacted on your social life?

Not really                      More or less                      Yes, it has                      N/A



26. Has the role of caring impacted on your mental health?

Not really                      More or less                      Yes, it has                      N/A



27. What do you do to care for your own wellbeing?

28. Has the condition of the person you care for changed since you have been known to the system?

- No
- If yes, how was the process of updating that with the local authority?



## 6. End and Demographics

This section is not compulsory, but it would help us to understand what are the demographics of carers in Newham.

29. Age:

30. Which of the following describes how you think of yourself?

31. Ethnic background:

- African
- Asian/ Asian British
- Black/Black British
- White British/ Traveller
- Chinese
- Iraqi
- Iranian
- Mixed/ Multiple races
- Romanian
- Somali
- Turkish
- Prefer not to say

32. English most spoken language?

- Yes
- If not, specify

33. Are you in....

7. Thank you for taking part in the questionnaire!

Find below further information that may be useful for you:

#### **Newham Joint Carers Strategy 2015 -2018**

This is a strategy to how best support carers in Newham for the period of 2015-2018 created by Newham council and the Newham CCG. The PDF document can be found [HERE!](#)

#### **More information about the Carers Assessment**

##### **What is a Carers Assessment?**

A Carers Assessment is simply a discussion with you that will help us understand the:

- > physical
- > emotional
- > practical
- > impact that caring has on your life and to ensure that your needs are taken into account.

This can be carried out at the same time as the assessment of the person you care for, or can be done separately and privately. You have the right to an assessment if you are providing unpaid support to someone else or if you are about to start caring. Also, as a carer, you have a right to have your needs considered when decisions are being made about support for the person you care for.

There is no charge for a carers assessment or information and advice. For carers who feel they need some support in their caring role, the Access to Adult Social Care Team is the first point of contact for all referrals and general enquiries.

#### **Access to Adult Social Care Team**

Call: 0208 430 2000 Option 2

Text phone:18001 020 8430 2000

Opening hours: Mon-Thurs 9am-5pm & Friday 9am-4.45pm

For more information visit: <https://adultsocialcare.newham.gov.uk/pages/home-page.aspx>

To contact the Healthwatch Newham team:

[Info@healthwatchnewham.co.uk](mailto:Info@healthwatchnewham.co.uk)

020 3866 2969

## In-depth Interviews – The hidden gaps in Carers' Support

### Participant information form

You are being invited to take part in a Healthwatch Newham project which focuses on exploring the needs and experiences of carers who live in the local area. We will ask a few questions about your caring duties, the support you receive as well as the difficulties you face to do your role. All information collected is anonymous. The data will be used to a general analysis and a report will be written and shared across Newham's healthcare boards with relevant recommendations to improve support for all carers.

### Do I have to take part?

It is up to you to decide whether to take part. If you later decide you want your data to be excluded from this research, please email the Healthwatch Newham team with your **unique participant code**.

#### 1. Who do you provide care for?

- A Friend    A family member    A neighbour    Other

#### 2. How many hours roughly a week do you spend caring?

- Less than 1-hour weekly    2-7 hours weekly    8-12 hours weekly  
 13-24 hours weekly    More than 24 hours weekly  
 Full time carer

#### 3. Are you officially known to GP and Adult Social care as a carer?

#### 4. Do you suffer from any physical health conditions?

#### 5. What about mental health conditions?

### Carer's Assessment

#### 6. Are you aware of the carer's joint strategy? Do you know what they have planned to support carers in the local area?

#### 7. Please tell me you experience of the carer's assessment.

- Have you taken part in it?
- How was it arranged? Where did it take place? Did they interview you together with the person you care for? How did it feel?
- What did you think of the questions? Do you think they touched on all the topics that were relevant for the care that you do?
- Did they ask you about mental health difficulties of the person you care for?
- Did you ask you about your health issues (e.g. physical disabilities, chronic illness)?
- What about your mental health ?
- How was the communication after the assessment? Did you have to follow up? Were you shown the report to see if you agree or not?

#### I. In regard to carer's assessment...

- What went well?

- What did not go well?
- What could have gone better?

**II. How was the support you received after the assessment?**

- What was good about it?
- What support was missing?

**Support for carers**

**8. Do you KNOW ABOUT the following sources of support available for carers in Newham?**

- Carers' Allowance benefit
- Free training courses including budgeting, safeguarding, managing long term conditions and others
- Carers' Emergency card scheme (make arrangements for the person you care for in case you are in an emergency)
- Carers' Discount card
- Peer support groups for carers
- Self-Management support programme (free 1-to-1 coaching sessions with a pharmacist for 12 weeks to help you manage your health conditions/needs)
- Newham free group therapy workshops (Newham Talking Therapies service)
- Blue badge for Hidden disabilities

**9. What services do you currently use?**

**10. How did you find about them?**

**11. Do you attend peer support groups for carers? If so, how is it? Is it helpful? What have they done for you? What impact has it had on you?**

**12. How is the experience of accessing health services with the person you care for (e.g. GPs, Health checks, mental health services, etc.)?**

- a. How is the experience of accessing health services for yourself (e.g. GPs, Health checks, mental health services, etc.)?'

**13. Do you have a job? If yes, how is the experience of having a job alongside caring?**

**14. How has caring impacted on your life? (on your career, job prosperities, education, volunteering, socialising, etc.)?**

- Has caring impacted on your health? How
- On your employment? How?
- On your social life? How?
- On your mental health? How?

**I. What do you do to care for your own wellbeing?**

**Reporting Changes**

**15. Has the condition of the person you care for changed since you have been known to the system?**

- Did you know that you had to report this? Did you know how go about it?
- If yes, how was the process of updating that with the local authority?
- How often have you had to change this?

## Demographics

Age: \_\_\_\_\_ Gender: \_\_\_\_\_  Prefer not to say

### Ethnic background:

- |   |  |  |
|---|--|--|
| <input type="checkbox"/> African                  | <input type="checkbox"/> Asian/ Asian British  | <input type="checkbox"/> Black/Black British |
| <input type="checkbox"/> White British/ Traveller | <input type="checkbox"/> Chinese               | <input type="checkbox"/> Iraqi               |
| <input type="checkbox"/> Iranian                  | <input type="checkbox"/> Mixed/ Multiple races | <input type="checkbox"/> Romanian            |
| <input type="checkbox"/> Somali                   | <input type="checkbox"/> Turkish               | <input type="checkbox"/> Prefer not to say   |

### English most spoken language? If not, which one

Yes No \_\_\_\_\_

### Are you in....

- |  |  |  |
|--|--|--|
| <input type="checkbox"/> Caring full-time? | <input type="checkbox"/> Part-time employment? | <input type="checkbox"/> Full time employment? |
| <input type="checkbox"/> Retired?          | <input type="checkbox"/> Education (Student)?  |  |

Date:

Participant no:

## REFERENCES

Braun, V. and Clarke, V., 2012. Thematic analysis.