Carers First
Haringey

Haringey
LONDON

Equalities Review of support for carers in Haringey
June 2021

Contents

1. Introduction

1.1 Overview

Haringey Council have commissioned Carers First to complete this review, looking into the needs, equality and equity of support for carers.

The Carers Strategy for adults in Haringey 2020-2023 was launched in October 2020. It was agreed that an equality review would act as a key starting point for the strategy, helping to underpin the implementation of other key areas of the strategy, and ensuring that Haringey meets the needs of all its carer population.

This review will support Haringey Council to understand the support needs of its ethnically diverse carers, improve their reach into these communities, remove the barriers to engaging and identify what their support needs are. The review seeks to answer the following

- • Where carers are under-represented
- • Where services are geared towards specific groups
- • How to talk about caring in a culturally sensitive way
- • Identify any barriers for these carers being identified and supported
- • Recommendations on reaching and supporting these carers

To provide some context, it is important to note that the research and interviews with carers and professionals took place in the Spring of 2021, at a time when carers were living in the midst of the pandemic. This may have influenced some of the responses.

1.2 Background

According to data from the 2011 Census, there are 254,900 people living in Haringey, and around 8% to 11% of these are unpaid carers. The Council supports fewer than 10% of the estimated number of carers in the borough. This indicates that a significant number of carers are not known to the service and may be unsupported.

Not only are more people becoming carers, but they are also caring for longer and at different points of time in their lives, meaning that their needs are becoming increasingly complex and variable over time. [1]

We also know that the caring journey is not static and the burdens facing carers change over time. Some of these points in time are predictable. For example, as a carer gets older their own physical health may deteriorate which means that they cannot fulfil their caring role in the same way. However, many are less predictable and relate to a carer's wellbeing, resilience and support mechanisms. With the right support to plan, and the right support available to carers in the community, (and for the person they care for) carers can better navigate their caring journey and actively seek information and support as their circumstances change.

Haringey is a diverse borough with a large ethnically diverse population and some areas of real social deprivation. As is evidenced later in the report, population projections indicate that these populations are going to increase, making it more important than ever that we begin to understand how to better reach and support these communities.

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[1] Facts about Carers (2019) Carers UK

2. Haringey Carers Strategy

In October 2020, Haringey Council launched their 2020 – 2023 Carers Strategy for Adults. This was co-produced with carers, statutory, voluntary and community sector partners.

The strategy focuses on five key themes developed from carer feedback about what already exists and what needs to improve. They are:

1. Your caring role – emphasising the need to recognise, identify and support carers in their role

2. Health and wellbeing – focusing on involving carers as experts, supporting their physical and mental health needs, and helping them adjust to changes in their caring role

3. Housing and managing at home – ensuring carers have a safe, appropriate and habitable housing, and are aware of the range of housing adaptations and assistive technologies on offer

4. Finances, benefits and debt – supporting carers to maximise income, minimise expenditure, manage debt, and access good quality, independent legal advice

5. Having a life of your own – developing opportunities to take breaks from caring, maintaining employment, and keeping carers' relationships at the forefront of our thinking

3. Carers First Strategy

Carers First has launched an ambitious new three year strategy 2021 – 2024. The strategy sets out Carers First new mission and vision, and its intention to make a material difference in the lives of carers over the next three years.

The strategy recognises the changing national and local environments, that carers are not one homogenous group and that working in co-design with carers will help to ensure that their support is relevant and inclusive to carers from all communities.

Whilst developing the strategy. Carers First talked to carers and stakeholders in the areas where they provide services, which includes Haringey. The findings from that work are included in the Appendix (See Appendix A)

4. Haringey Demographics

The total resident population in Haringey is 271,222[2]. Haringey Council estimate that there are between 20,000-27,000 carers in Haringey. However, fewer than 10% of carers in Haringey are currently formally registered[3].
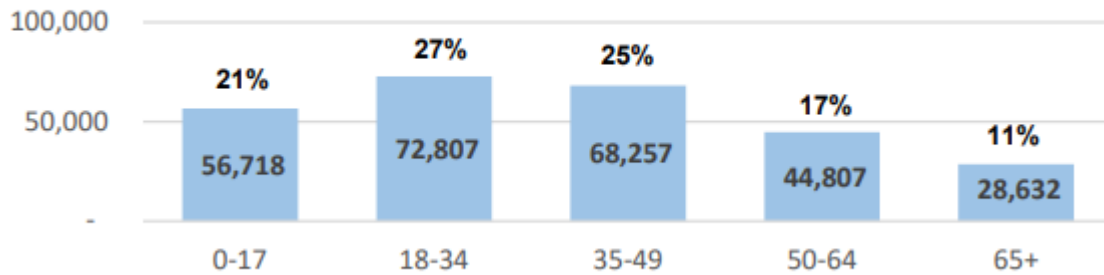
4.1 Gender breakdown

50.7% men
49.3% females

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[2] State of the Borough April 2021, Haringey Council
[3] The Carers Strategy for adults in Haringey 2020 - 2023

4.2 Age

Age Breakdown (2020 Proj.)

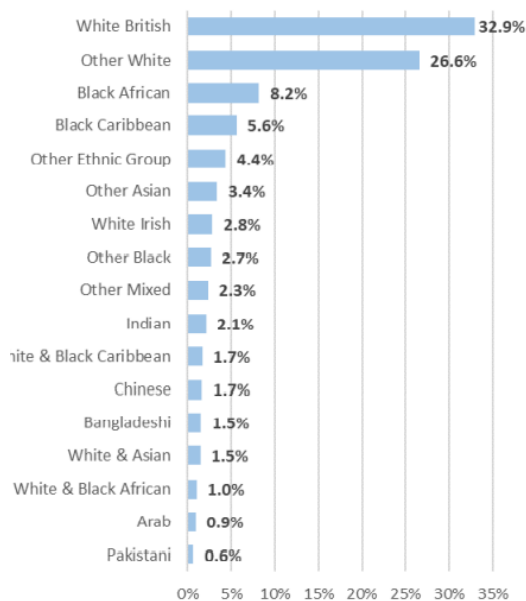| Age group	Population	Percentage
0-17	56,718	21%
18-34	72,807	27%
35-49	68,257	25%
50-64	44,807	17%
65+	28,632	11%

Source: GLA Housing Led Population projections (2018 based)

The highest expected growth in the 2018-based population projections (to 2030) is in the 65+ groups, with 65-84 year old population growing from 25,348 to 33,076 (+30%), and 85+ growing from 3,285 to 3,897 (+18.5%)

The working age population will remain the largest population overall.[4]

Distribution of Population by Ethnic Group Haringey 2020 (Proj.)

Ethnic group	Percentage
White British	32.9%
Other White	26.6%
Black African	8.2%
Black Caribbean	5.6%
Other Ethnic Group	4.4%
Other Asian	3.4%
White Irish	2.8%
Other Black	2.7%
Other Mixed	2.3%
Indian	2.1%
White & Black Caribbean	1.7%
Chinese	1.7%
Bangladeshi	1.5%
White & Asian	1.5%
White & Black African	1.0%
Arab	0.9%
Pakistani	0.6%

Source: GLA Ethnic group Population projections (2016 based – No 2018 base available yet)

4.3 Ethnic minorities

67.1% of the Haringey population are from an ethnic minority or a non-White British group.

Approximately 16.5% of residents in Haringey are from Black ethnic groups and one in ten are Asian (10.3%)

30% of Haringey residents do not speak English as their main language. Of those whose main language is not English, one in four (24%) either do not speak English well or do not speak it at all.

Haringey's population is expected to increase by 5% by 2030, to 284,989, with the largest percentage growth in older age groups (65+), other ethnic groups and other White ethnic groups.

The greatest proportional population increase will be among older people from ethnic minority groups.

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[4] GLA 2016-based population projections (2018-based)

4.4 LGBTQ+ community

Based on 2019 mid-year estimates, Haringey's gay, lesbian and bisexual community consists of over 8,900 gay and lesbian residents aged 16+, and over 4,400 bisexual residents aged 16+.[6]

It is difficult to estimate the trans population as estimates vary widely. The latest national estimates range from 65,000 to 300,000.

4.5 Deprivation

Haringey is the 4th most deprived borough in London, with deprivation more concentrated in the north east. There are significant gaps in healthy life expectancy between populations in Haringey: the gap in healthy years of life between richest and poorest deciles is 15 years for men and 17 years for women.[7]

This map shows where carers who are registered with Carers First live. The largest numbers are carers supported by Carers First live in some of the most deprived areas within the borough.
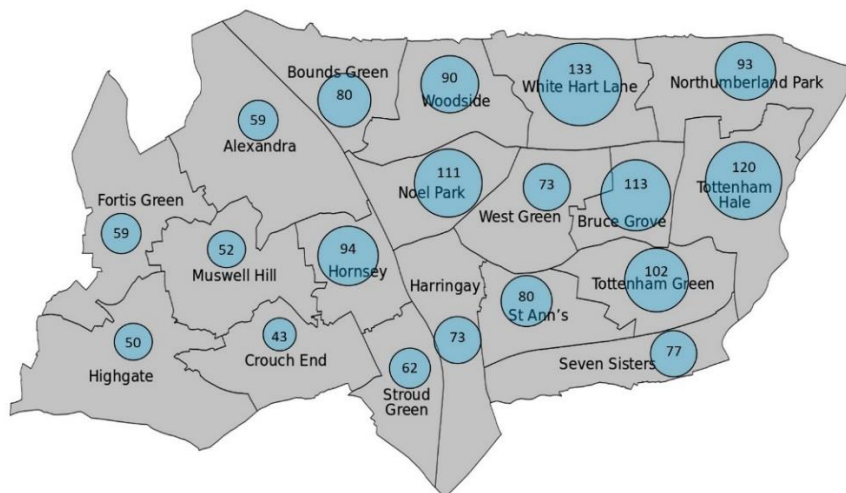
5. National picture of Carers

5.1 Numbers of carers

In 2019, using population projections from the ONS and polling by Carers UK it can be estimated that 8.8 million adults in the UK are carers.[8] Every year over 2.1 million adults become carers and almost as many people find that their caring responsibilities come to an end[9]. In addition, 3 in 5 people will be carers at some point in their lives[10].

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[6] State of the Borough April 2021

[7] State of the Borough April 2021

[8] Carers UK, Facts About Carers 2019

[9] Analysis conducted for Carers UK by Michael Hirst (2014) Transitions into and out of unpaid care

[10] Carers UK, (2001), It could be you – the chances of becoming a carer

5.2 Gender breakdown

58% of carers are female and 42% carers are male[11]

- 1 in 4 women aged 50-64 have caring responsibilities, compared to 1 in 6 men[12]
- Women have a 50:50 chance of providing care by the time they are 59; compared with men who have the same chance by the time they are 75 years of age
- Women are more likely to be sandwich carers (combining eldercare and childcare) and are also more likely to give up work in order to care[13]
- 59% of carers aged over 85 are male, and 31% are female[14]

5.3 Age breakdown

One in five people aged 50-64 are carers. Many carers are below state pension age and the peak age for caring is 50-64 - over 2 million people in this age bracket are carers.[15]

Almost 1.3 million people in England and Wales aged 65 or older are carers. The number of carers over the age of 65 is increasing more rapidly than the general carer population. Recent polling suggests that there could now be over 2 million people aged 65 or older who are carers. Older carers, those aged 85 and over, are most likely to be a carer for someone with dementia (53.6%). For over 50 per cent of this age group they are also supporting care needs related to physical disabilities, therefore is likely that the cared for person has multiple needs. 90.1% of older carers, those aged 85 and over have caring responsibility for someone aged 75 or over.[16]
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5.4 Ethnic minorities

Carers UK state that carers from ethnic minorities are less likely to be receiving practical and financial support with caring and more likely to miss out on accessing support for longer – often because of a lack of advice and information and struggling to access culturally appropriate services.[17]

According to Carers UK
- 35% of all carers in poor health in London are from ethnic minorities
- Carers from ethnic minorities are more likely to be in poor health compared with White British carers[18]

5.5 LGBTQ+ carers

There are no clear statistics on LGBTQ+ carers. The charity Stonewall estimates that 5-7% of the population is gay, lesbian, bisexual and transsexual. Based on the estimates from

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[11] Census 2011
[12] Census 2011
[13] Carers UK (2000) It could be you
[14] Census 2011
[15] Census 2011
[16] Personal Social Services Survey of Adult Carers in England (SACE) 2016-17 Published 03 August 2017
[17] Echoing the findings of Carers UK (2001) Who cares wins: statistical analysis of the Census
[18] Carers UK (2011) Half a million voices: improving services for BAME carers

Stonewall that 3.7 million people in the UK are LGBTQ+, Carers UK estimates there are 390,000 LGBT carers in Britain. [19]

5.6 Disability

The 2019 GP Patient Survey found that carers are more likely to report having a long term condition, disability or illness than non-carers, 63% of carers compared to 51% of non-carers[20]

According to the NHS Information Centre Survey of Carers in Households, 27% of carers were in receipt of Disability Living Allowance because of their own disability or ill health[21]

Carers who have an illness or disability themselves were also significantly more likely to be in debt and have much higher levels of debt than other carers, with these carers reporting this resulted from a combination of their own additional disability-related costs and reduced earnings. Of respondents to Carers UK's State of Caring 2016 survey, 57% of those who considered themselves to have a disability said their financial circumstances were affecting their health.[22]

5.7 Working carers

According to the 2011 Census, around half of the UK carers also work. Over two million work full-time and one million work part-time. Although part-time working is more common, carers are more likely to give up work completely as they struggle to move to part-time hours.[23]

Half of carers cited problems with accessing suitable care services as a reason they gave up work or reduced working hours.[24]

5.8 Deprivation

22% of carers live in poverty, this compares to a national figure of 16% living in relative poverty.

- Poverty levels are highest in the working age carer population with poverty levels increasing to 37% for carers who provide over 20 hours of care a week[25]
- 39% of carers described their financial situation as 'struggling to make ends meet[26]
- 40% of carers have missed out on financial support because of not getting the right information and advice[27]

[19] Carers UK, Facts About Carers 2019

[20] NHS England (2019) GP Patient Survey 2019

[21] NHS Information Centre for Health and Social Care (2010) Survey of carers in households 2009/10

[22] Carers UK (2016) State of Caring 2016

[23] OECD (2011) Help wanted? Providing and paying for long term care

[24] Carers UK (2014) Carers and family finances inquiry report 2014

[25] IBID

[26] Carers UK (2019) State of caring 2019

[27] Carers UK (2016) Missing out: the identification challenge

6. Methodology

6.1 Timing

Interviews and surveys with carers and professionals took place from March to May 2021, in the midst of the pandemic, whilst many restrictions were still in place. Some services had closed, albeit temporarily, and many others were operating limited services. This was not referred to directly in many of the responses, but it's important to provide some context.

6.2 Carers

We interviewed a total of 14 carers from Haringey. All carers were registered with Carers First and had received support from the service. Interviews were completed via a phone call and a set of questions were asked (see Appendix B)

In addition, a survey was emailed out to Haringey carers registered with Carers First . A total of 650 carers received the survey and 34% opened it. 108 carers responded.

6.3 Partner organisations

A total of 38 partner organsations from across Haringey were invited to take part in a survey. The survey was also shared via newsletters, emails, and the Navnet WhatsApp group. 13 organisations responded either through completing the online survey or via telephone. A list of these organisations can be found Appendix C.

The survey questions can be found in Appendix D.

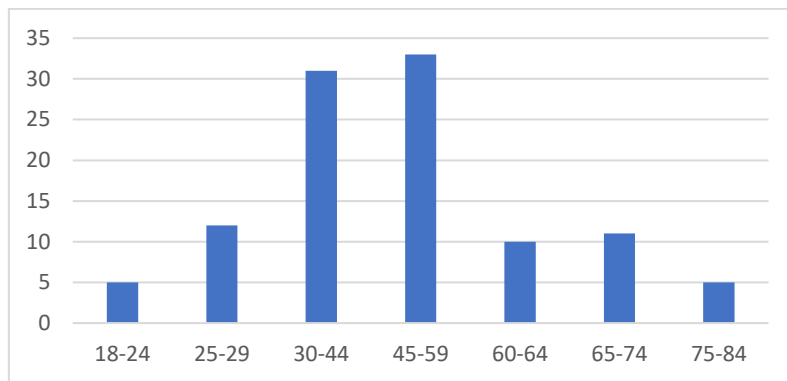# 7. Findings

7.1 Carers Survey Results

A total of 650 adult carers registered with Carers First received the survey. 108 carers returned a completed survey.

Gender

Of those who responded

- 70% identified as female
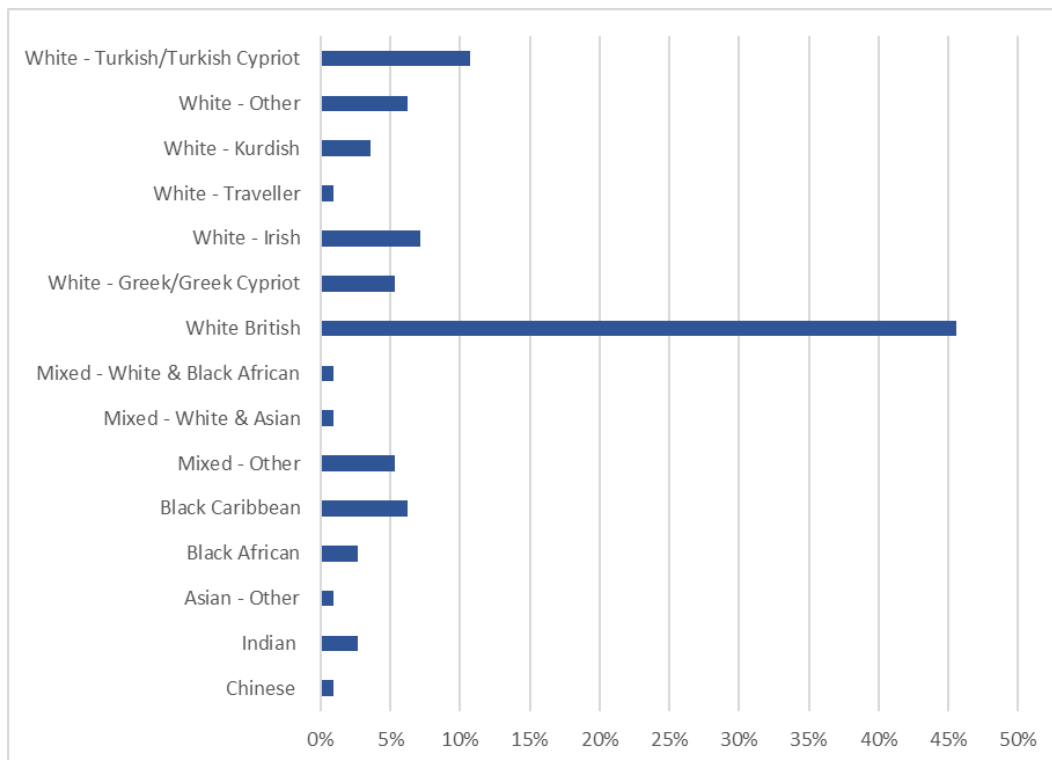- 27% identified as male
- 3% preferred not to say

Age

Age range of respondents

The majority of respondents were aged between 30 and 59 with 31% being aged between 30-44 and 33% being aged 45-59. This correlates with Carers UK's evidence that most carers are of working age.

Ethnicity

Ethnicity of survey respondents

Of those who responded 46% of carers referred to themselves as White British, 7% as White Irish and 6% as White Other: a total of 59%. According to the GLA statistics, 32.9% of the population are White British, 26.6% are White Irish and 2.8% are White Other: a total of 62.3.

7.2 Carers receiving support

The carers were asked if they had received support for their caring role. The results from this question are below. Note that the carers we interviewed defined support as being practical, such as respite, day care, advocacy and help with benefits. They tended not to view softer services such as information, advice and wellbeing groups as being support.

By gender
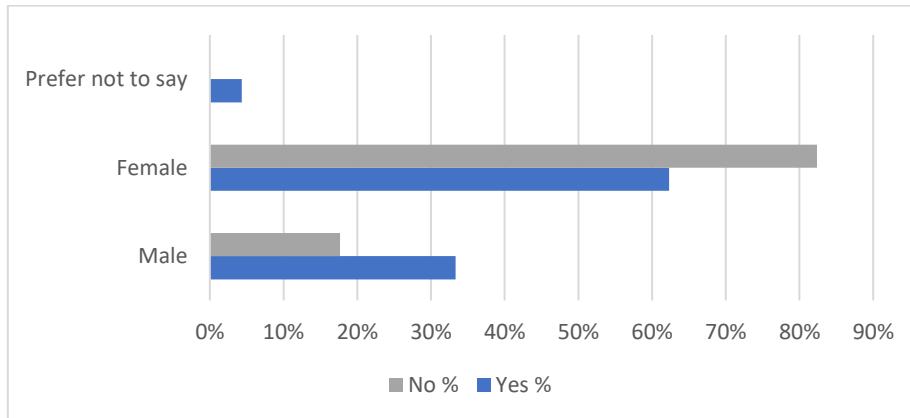
Carers receiving support by gender

According to the responses, although more females are registered as carers, the data suggests that males have received more practical support than women.

Age
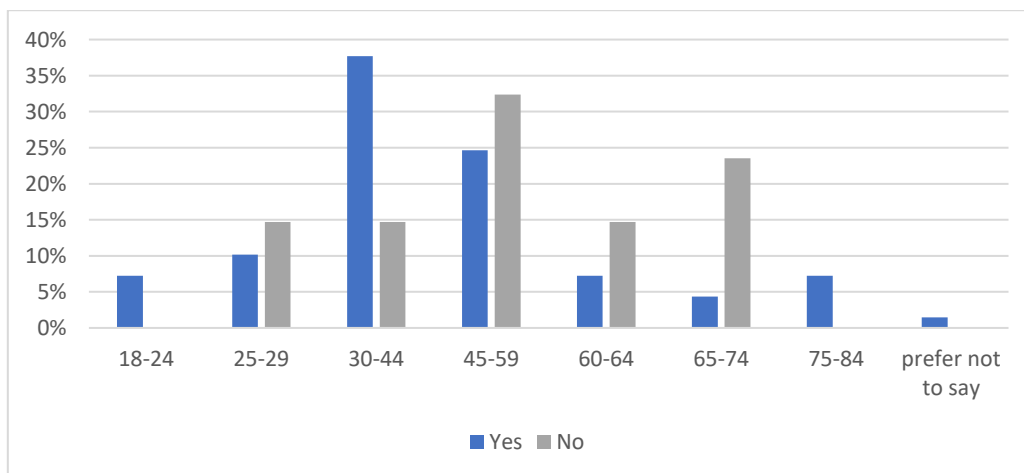
Age of carers

87% of the carers who responded and said they had received support are of working age. This correlates with national figures which say that most carers are under state pension age. However, nationally the peak age for being a carer is 50-64. Our respondents are spread more equally with 38% being aged 30-44 and 25% aged between 45 and 65.

Looking at our respondents, if you are aged between 60 and 74, you are less likely to receive support for your caring role.

By ethnicity
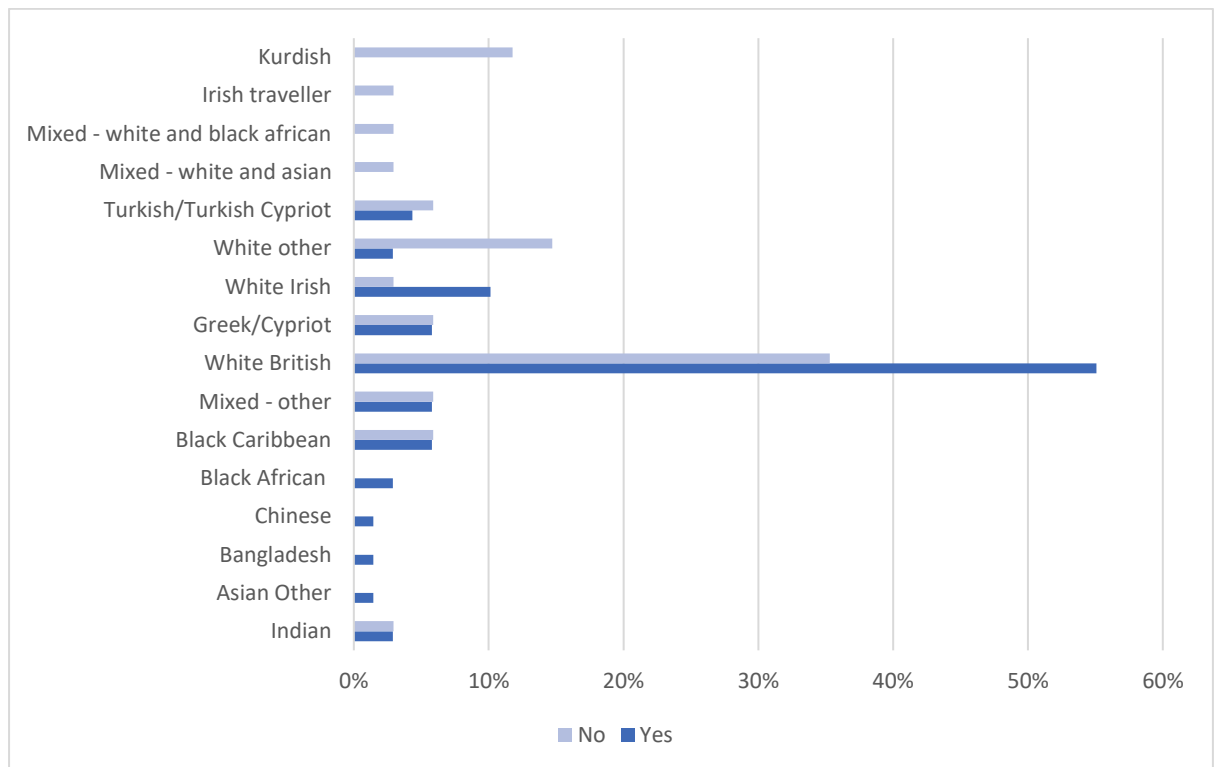
Ethnicity of carers

The largest number of carers who say they haven't received support are the White Other group followed by the Kurdish carers. None of the Kurdish carers, Irish Traveller, Mixed – White and Black African and Mixed – White and Asian say they receive any support at all. Only the White British and White Irish carers report significantly higher numbers of receiving support than not

Type of support received

Carers were asked what type of support they had received, and their responses fell into the following main areas:

- care packages
- Benefits advice
- Wellbeing groups
- Emotional support
- Financial help, such as a grant
- Aids and equipment
- Information and advice
- Day centre/respite
- Support from GP/social prescriber
- Support from specialist organisations
- Carers assessment
- Dementia support
- Support from employer

No support received

Carers who indicated that they had not received support were asked why that was. Answers fell into the following categories:

- No appropriate support available.
- Difficulty accessing help.
- Unsure what support was available.
- Cultural and language barriers

'The Carers might not know where to get the support from or it can be because of language barriers'

'I see amongst my friends, particularly those caring for elderly parents, that they are really struggling and are weepy and exhausted'

'When you're caring for someone it's all that you can do to care for the person. Trying to figure out complex support systems is challenging'

'They do not always understand the cultural and religious differences to tailor the care and support needed to reflect this'

Diversity of services

We asked the carers if there were services in place for carers from all backgrounds and cultures, and 53% of carers said there were. However, 59% of the carers who said yes were White British carers, with the next largest figure being White Irish carers. Of the carers who said no, here is a breakdown of their ethnicity:
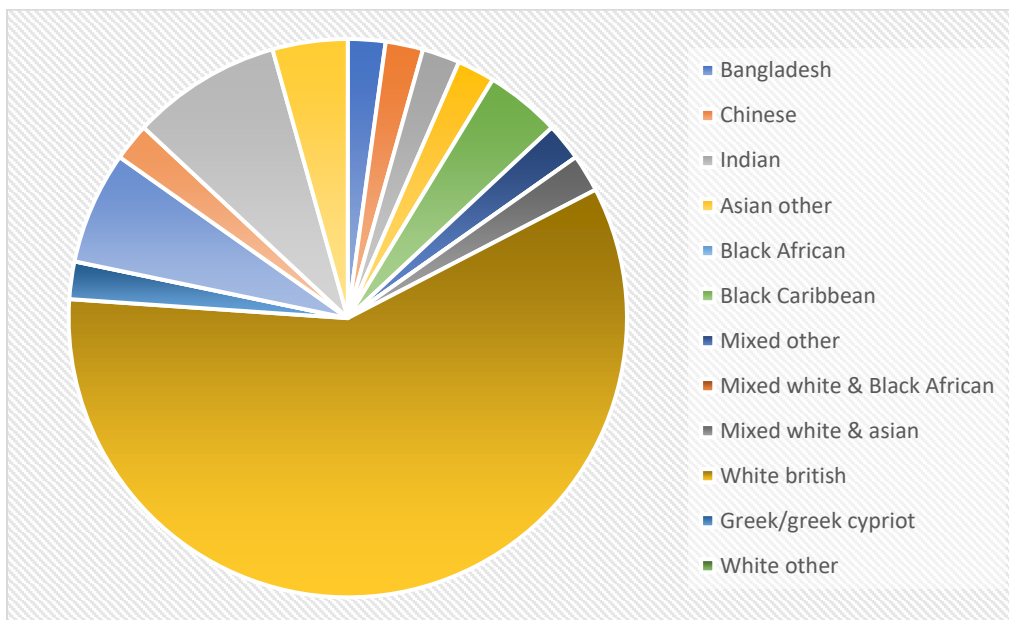
Of the carers who answered no, there is a much greater mix of ethnicities.

Asking for help

Carers were asked what the barriers are to asking for support. The responses fell into the following themes:

- Fear of the consequences
- Fear of judgement
- Time
- Process is too difficult
- Not identifying as a carer
- The person they care for might not be used to strangers'

'I don't want to lose control of my mums' decisions and I guess I am suspicious of local authorities'

'Fear the removal of a loved one in favour of a home.'

'I think some carers also feel that it is a weakness or a failure on their part if they are not coping, and they burn themselves out.'

'it's too much hard work and effort to get the little help that exists'

'Many don't even know they can ask for help or even qualify for benefits'

'Frequently when a Carer needs support, they are probably worn out and need the help immediately, which they will feel they will not get so there is no point in asking'

'There is no time or headspace to do it when you're caring for someone.'

'The forms which need to be completed to get help are long and stressful'

'Caring is seen as part of their role as a daughter, in the same way that their mothers looked after them, now the tables are turned.'

Improving services
Carers were asked to tell us what they would find helpful, and how could services be improved. Their responses fall broadly into the following categories:

- Activities
- Improve the processes
- Financial support
- Information
- Peer support

'Fun days and respite'

'Having evening and weekend activities'

Consistent advice, a named social worker or at least a named case worker who gets to know the family'

'A sympathetic and understanding and honest approach about what can be available, cost, constraints etc rather than a protracted approach where nothing happens'
'Quick, simple response for support. Waiting many months for a carers assessment is very stressful'

'I have had to put a lot of energy, that I didn't really have while battling access to services for my son in order to receive support, It shouldn't be like this.

'Coordination with GPs, social workers and mental health services'

'Once diagnosed then recommend straight away to Clubs or Units that provides help'

'To be given more financial support and not to have to fight for the one-off carers grant'

'More one-to-one support on how to access and support with the completion of Forms'

'A one stop shop where all their needs can be met'

'Webinars on specific topics where carers can ask questions and can be signposted to the services that will help them with their issues'

'There will be some Carers that do not have computers or smartphones'

'Other carers helping other carers, especially from their own background culture, who have 'drunk the cup of sorrow' even if it is only emotional support'

7.2 Adult Carer Interviews

A total of 14 carers were interviewed in more depth to hear their experience and views on the support and services for carers available in Haringey. The carers interviewed were from a range of ages and ethnic groups. Those interviewed were caring for loved ones with a variety of conditions including mental health issues, dementia, stroke, and learning disabilities. Some carers had health issues of their own. Therefore, some of the responses given relate to support for themselves and their cared for.

Carers were asked whether they had received support in Haringey and if not, why not. They were also asked for their opinions on culturally specific services for carers, barriers to carers asking for help, how we can reach more carers within different communities, and what improvements could be made to services in Haringey. From the feedback given, we were able to identify and collate the common themes that emerged from the interviews. These are detailed below:

Support in Haringey

Many carers expressed that they were not aware of all the support that is available to them, and did not know if they would qualify to receive help. Carers stated that at times during their caring role they had struggled to get support and appropriate services in Haringey. Some carers had made enquiries about support but received no response. Many of the carers interviewed were in receipt of welfare benefits.

Covid 19 did have an impact on carers accessing services, however it was felt that it was difficult prior to the pandemic. Several carers expressed that they have had a poor

experience with carers assessments, stating that they did not receive any further correspondence with professionals after completing the forms.

> 'Haringey is one of the worst boroughs...Social care is very hit and miss, more often miss...sometimes you don't get help point blank...and seeing is believing.'

> 'No one has approached me after assessment- No one has assisted me from council… No follow ups…Takes a lot of red tape to get through to anyone'

Many carers expressed feelings of being left disheartened and unsupported. Carers felt that professionals should have a better understanding of carers and their needs. Some felt that they should be listened to more and that help should be given sooner rather than later.

Some carers felt that professionals lacked training and did not relate well to the real needs of carers.

A few carers that were interviewed had very positive things to say. They were pleased with the help and support they had received from professionals to help them complete grant applications for IT equipment and phones. These had helped them to connect virtually with other carers, attend peer support groups, health and wellbeing groups, training opportunities and workshops as well as exercise classes.

> 'Carers First has been the best thing for advice and support as well as assistance from social services in Haringey Council'

> 'Advice, guidance, encouragement, discounts, telephone support, claiming benefits and carers rights'

> 'good quality assessor, whom I can contact if/when things became problematic'

> 'useful/free equipment (bed, commode, walkers) & easy access to company that repairs/replaces'

> 'very good hospital services, particularly, after diagnosis was made'

> 'I received support after battling for it for a very long time'

> 'Gaining advice on other agencies to make contact with regards to my carer concerns.

> 'Participating in social stress relieving activities and exercise also therapeutic art development session'

Culturally specific services

Carers interviewed were asked if they were aware of or had used culturally specific services. The majority responded that they were unaware of any such services.

Carers expressed that there is not enough support for the individual needs and circumstances of carers from ethnically diverse communities. It is thought that not everyone is able to handle the complex system. If carers have vulnerable circumstances such as a disability, language barrier or condition. they may need someone to advocate for them and help them to receive the support that they are entitled to.

> 'Caring falls disproportionately on women and those from ethnic minorities'

'Possibly lack of confidence at making their needs known. Trying to push it under the carpet. Foolishly trying to do everything on their own. Not wanting to show weakness'

Carers highlighted that Haringey is a very diverse borough with many different communities Some spoke about language barriers and the limited amount of information available in common spoken languages.

It was felt that in some communities the culture is for everything to stay within the family, and that carers may not seek information or support from outside of the family. It was also noted that in some cultures women are discouraged from educating themselves and seeking information, and that this has an impact on the help and support sought or accepted.

'Everyone cannot speak English. They are therefore less confident in asking for help. Many also prefer help coming from those who are aware of and sensitive to their culture ie. those who have the skill of cultural awareness. They are less likely to criticise, get angry, etc.'

'They do not always understand the cultural and religious differences to tailor the care and support needed to reflect this'

Barriers to carers asking for help

Repeated failures on behalf of professionals was a common theme, where carers had sought support and advice and had little or no response from professionals. This has resulted in some communities mistrusting the services offered. Carers felt overlooked and believe that professionals should be more helpful, compassionate and have more empathy. For those carers who did receive responses from professionals they felt that they had to speak with multiple professionals and organsations before receiving any help or support

'A lot of lip service…Carers are poorly looked after...carers are the actual professionals and need much more recognition'''

'We should be treated with more respect…more compassion and empathy'
'Carers are the real professionals…hate when people just say we need more recognition'

'Too much faffing around…too much paperwork… can't always remember and then I don't have anything to hand…it's difficult to look online sometimes'

'What they offer is not individualised and personal to our needs…can't get our hopes up'

Time restraints were identified as a further barrier. Many carers have a very demanding caring roles and some are unable to leave their cared for. This makes it difficult and stressful for a carer to spend long periods of time researching and trying to find out information. These time constraints also impact on the carer, making it difficult to attend support groups, meet other carers, and take time for themselves.

Reaching a wider scope of carers

Carers suggested that more publicity and advertising in general places such as in hospitals, GPs, pharmacies, health centres etc which would help to raise awareness and reach a wider range of carers.

Helpful services that can be developed

The carers suggested that to engage carers from different communities, information should be available in different languages. Information needs to be easily accessible.

7.3 Organisations and services

We received responses from 13 organisations within Haringey, representing the voluntary and statutory sectors (see Appendix C for a list of these organisations'). The following is a breakdown of their responses.

How do the organisations support carers?

Most of the organisations do not specifically support carers, but rather carers are amongst the wider group that use their service; in some situations, the main service is provided to someone with a health condition or disability, and the carers support is incidental.

> 'We are a group of carers and people living with young onset dementias - self-supporting.'

> 'Some of the people we support are also carers both formally and informally, so we support them with getting support for their caring activities. These are predominately people with learning disabilities and/or Autism'

> 'Family and carers of our patients access psychosocial support, which is led by our SW team. We provide face to face, group, virtual support and are compiling an online directory of resources for those caring for someone who is end of life and known to one of our clinical teams, including In-Patient Unit'

> 'We have our own Carers Policy which includes guidance for CYP & adult carers about Carers passports, support available etc- pledged to support & implement John's Campaign across COOP (actions to extend across all adult wards included in our PE Strategy) - we are a key partner signed up to supporting Carers as part of Haringey's Carers Strategy'

Do they support any specific groups of carers?

Carers First is the only charity commissioned to support all adult carers across the borough. Most of the other organisations supported carers who looked after someone with a condition such as dementia, individuals who misused substances and those who support someone with a physical disability.

Do carers from all groups, backgrounds and cultures access their services?

There were mixed responses from the organisations who responded, with most saying that their services were not accessible to all carers. Some cited language barriers as an issue:

> 'Turkish speakers are always needed - many Turkish carers are of a generation where they learnt little English but will have lived here for decades'

'Workers of South Asian descent with languages such as Bengali and cultural awareness of the history of caring in South Asian family. Whilst unlike our neighbouring boroughs - the south Asian community in Haringey is seen as comparatively small. Regardless I come across a lot of South Asian carers, and it is often more of expectation for family members to be carers. I would love to be able to refer to a specialist team that could help engage this group'

'We would use google translate to communicate with carers if necessary'

One organisation said that they have to work harder to reach carers in the more deprived areas of the borough. They said that carers are unaware of the support and have lower expectations generally that there will be help available.

There is also a lack of information being collected about the carers who do access support:

'We don't know how many of our members are carers. It would be interesting to find out but we are only very gradually managing to persuade them to tell us basics about their age, ethnicity, disability status, etc.'

'Yes, we see people from all backgrounds and cultures, and while they some may not formally recognise themselves as carers we do have discussions around this with them to access support'

Some organisations are looking to make improvements:

'The Society is looking at the support needed by different ethnic groups'

What are the barriers to accessing support?

There were several common themes raised by the organisations who responded, these themes are similar in context to those reported by the carers.

- Identifying as a carer
- Trusting the services
- Time and their caring role
- Unaware of support available
- Cultural and language barriers

'They do not relate with the status of carer and those in end of life situations find the process of accessing support is too lengthy. Carers have other commitments eg. work, study, childcare'

'They are too busy and underestimate what they do and the toll it can have'

'There are issues around admitting there is an underlying care need, particularly with mental health.'

'I have found some evidence that lack of good information contributes to this problem, as does an expectation that they would have to pay a lot now, and lack of trust or confidence in the quality of services provided by formal care services'

'There is a stigma to some health conditions too such as autism, mental health and dementia - this prevents carers from coming forward'

'Carers are so distressed they can't engage properly'

'Again, as I often get patients who are already in a difficult situation, they seem to be unable to understand that they need to get help for themselves. They are some of the most frazzled clients I have worked with - by the time I am speaking to them they are in constant crisis mode.'

'They feel completely undervalued and panicked - they don't see how a service can help them when they haven't been helped before'

'They often don't prioritise events that support them '

'They are not sure who they can go to for support and what sort of support is available.'

'Pride, shame and cultural norms'

'Some people are culturally expected to care, particularly women'

How can we reach more carers?

The answers generally suggest that to reach more carers, organisations need to be more embedded in the community and places where carers spend their time. The main suggestions include:

- Ambassadors/Champion model
- Working in partnership with community groups

'Get carers on board and spread the word'

'Approach groups, religious/ cultural organisation and raise awareness about the support available to carers.'

'Needless to say information in community languages and outreach to their community groups and centres is important. Selby Trust, the several mosques and the several Turkish/Kurdish/Cypriot organisations plus the Caxton Road Hub could probably help.'

'Liaising with organisations/professionals that are accessed by those who don't engage'

'Provide information in more languages.'

'Work closely with the Social Prescribers to help identify carers, and check the Dementia register held by GPs'

And as organisations we should all be:

'Working in collaboration and ensuring carers are recognised and valued for their lived experience and having a strong organisational carer narrative on all our social media platforms.'

What would be really helpful for carers?

We asked the organisations for suggestions about support that would be helpful for carers and help to improve the existing support. The answers fell into the following categories:

- Peer Support
- Co-production
- Flexible support
- Clear and simple information and advice
- Accessibility
- Practical help
- Improve access to social care

'Dedicated support groups to allow recognition of demands of caring. Ie not just info/advice/support - time with other carers to share and understand and voice feelings- and to be heard and understood.'

'Listen to carers concerns and be let them be part of the solution'

'Many carers are not older people with time on their hands to attend meetings (traditional view of carers). Many carers are younger mums with children, and it may be good to have carers services within schools for both young carers but also for adult carers.'

'In regard to Autism - clear information on diagnostic pathways and what to expect.'

'A way to access services that helped - too many are signposted to other organisations'

'A directory for carers that includes key contacts including emergency support'

'Universal calendar showing what's going on across the borough (all groups'

'More simplified information which is also available in some common languages'

'Haringey website - some carers find it difficult to navigate, unaware of what to look for.'

'Easier access to local authority services'

'Post items to carers, don't assume they have internet access'

'Carers identification cards'

'Support with digital skills and provision of tablets'

'Support with benefits and form completion'

'Respite care is a big issue as is a greater supply of local placements for severely autistic adults.'

'Activities to do together with cared for'

'Waiting a long time for assessment is an issue'

'Fast track system for carer assessments when cared for person is end of life'
'Shorter statutory carer assessment tool and process'.

'It would be good to have a written guide on carers assessments that explains what to expect and gives advice and tip'

'To access local authority care and support in Haringey is extremely hard.'

8. Conclusion and recommendations

8.1 Conclusion

The purpose of this review is to support Haringey Council to better understand the support needs of its carers, improve their reach into the communities where carers live and work, remove the barriers to engaging and identify what their support needs are.

The findings of this report go some way to achieving this. The carers and professionals involved have strong views about what is not working currently, and many suggestions about how to improve the situation.

However, it was also difficult to engage with some of the smaller, informal community groups and their views are therefore not represented in this report. This could be a direct result of the pandemic as some organisations may have temporarily closed, but it could also be that these communities are disengaged from mainstream services.

It was also difficult to obtain responses from the health sector and hospitals. Undoubtedly carers will spend much time within health settings and so it's important to undertake some work to identify how carers are currently being supported so that the gaps can be addressed.

It is also apparent from the research that very few organisations collect evidence on the numbers of carers accessing their service. This makes it difficult to fully determine what services carers are receiving and ultimately where the gaps and inequity are. More work needs to be done to encourage organisations to identify carers and to monitor their use of the service. It is likely that opportunities are being missed to provide support to carers.

On a positive note, the organisations and professionals who did feed into this report demonstrated a will and commitment to improving support for carers.

8.2 Recommendations

These recommendations are based on the findings from the research undertaken with the carers and professionals who took part in this research. The recommendations have been grouped according to the five themes of the Carers Strategy for Adults in Haringey.

1. **Your caring role: emphasising the need to recognise, identify and support carers in their role**

   i.   Build a network of Carer Ambassadors who will:
        a. raise awareness of carers within their workplace, health setting, faith group, and any other community setting
        b. act as champions for carers, encouraging people to recognise themselves as carers and to seek support
        c. act as a link between professionals and the community, providing feedback on gaps in services and raising issues
        d. inform carers about the support and training available to them
   ii. Partnership working
        a. Develop a network of organisations who support carers, encouraging integration, and giving them a forum to share information which encourages signposting and referrals
   iii. Fund specific advocacy services for carers from ethnic minorities which supports them to access help that is relevant to their caring role
   iv. Carer awareness sessions:
        a. Work with carers from ethnic minorities to create a series of carer awareness sessions which will be delivered to staff from the health and social care sector, including the social prescribers. These sessions will seek to explain how caring is viewed within their culture, and how they can be best supported
        b. These sessions can be filmed so that they can reach a wider audience
   v.   Evidence: ask organisations to monitor and record the number of carers who access their service; these records should include specific information on gender, ethnicity and sexuality
   vi. Information campaign:
        a. Develop an Information campaign which aims to help carers identify themselves and explains the value of accessing support
        b. Work in co-production with carers to ensure that the information is clear, simple and accessible
        c. Produce a series of carer stories, written and filmed, which represent the variety and range of carers and their roles
        d. The campaign should be delivered in partnership with community and voluntary sector organisations so that it can reach the places where carers go
   vii. Social Care system:
        a. Work in co-production with carers and organisations who support carers to develop a new carers assessment process, one which is accessible for all
        b. consider a fast-track service for carers looking after someone who is at the end of life
        c. Develop pathways so that carers and organisations who support carers can provide ongoing feedback
   viii. One point of contact: promote one contact point for carers and professional to simplify the process for carers and professionals to access information and advice

ix. Digital support: the pandemic has shown us that some carers find virtual meetings and support convenient. Collect learning from carers and professionals about what has worked well so that this can be continued

x. Accessibility:
    a. services should be accessible to all, and organisations encouraged to demonstrate how they will achieve this
    b. Written information: Keep it simple: where possible, all written information should be available in plain language, written concisely, and in a large font.
    c. Translation: work in partnership with community organisations and Ambassadors to determine when translated materials are appropriate

xi. Develop a service of training sessions which cover a range of relevant topics, such as lifting and handling safely, caring for someone at the end of life, managing medication, health-specific subjects

2. Health and wellbeing: focusing on involving carers as experts, supporting their physical and mental health needs, and helping them adjust to changes in their caring role

i. Provide dedicated counselling services for carers

ii. Promote existing peer support opportunities for carers, and look to increase the range of support available, including an offer for carers from the LGBTQ+ community, working carers and culturally specific groups

iii. Health sector
    a. Work with GP surgeries so that they become more carer-friendly: providing a carers register, flu vaccines, regular health checks and information on support for carers
    b. The CCG to send text messages to carers who are registered with GP surgeries, encouraging them to register as carers and access support

iv. Fund carers support staff to work within health settings who will raise awareness of carers, identify carers, provide information and advice, and signpost and refer on for further support where necessary

3. Housing and managing at home: ensuring carers have a safe, appropriate and habitable housing, and are aware of the range of housing adaptations and assistive technologies on offer

i. Work with the London Fire Brigade to promote the uptake of free fire safety checks and smoke alarms around the home; use the network of partner organisations and Carer Ambassadors to support with the promotion

i. Develop training and information for carers on obtaining aids and equipment for the person they are caring for; work with the Carer Ambassadors to promote this training

ii. Consider a fast-track referral process to the Occupational Therapy service for carers

4. Finances, benefits & debt: supporting carers to maximise income, minimise expenditure, manage debt, and access good quality, independent legal advice

i. Fund more benefits advisors to assist carers with benefits and grant claims

ii.   Work in partnership with community and voluntary sector organisations to deliver ongoing workshops and information on money issues, including financial management, debt, welfare benefits and grants available: ensure the information and workshops are accessible to a wide variety of carers by developing them in co-production with carers

5. Having a life of your own: developing opportunities to take breaks from caring, maintaining employment, and keeping carers' relationships at the forefront of our thinking

  i.   Digital inclusion: deliver training programmes which support carers to get online; provide free tablets and IT equipment
 ii.   Respite: this should be easily accessible and low cost or free
iii.   Provide more joint activities for carers and the person they are looking after
 iv.   Provide activities in the evening and weekend as well as during the day
  v.   Carer-friendly employers: deliver carer awareness sessions to Haringey employers, encouraging them to understand the benefits to supporting employees who are also carers

11.0 Appendix

Appendix A

Carers First: Findings from online survey of carers in Haringey, August 2020

Haringey indicators of impact (number of surveys: 21)

- **How did you find out about Carers First?**

24% found out from the local council/social services, **19%** from a GP or health professional and **19%** from word of mouth.

- **Profile of carers**

83% were female**.**

23% were in employment (full or part-time).

51% of carers had their own long-term physical or mental health condition.

42% were caring for their spouse; **25%** were caring for a parent/parent-in-law and **11%** for more than one person.

42% cared for more than 90 hours a week. **30%** cared for 50-90 hours and **15%** 20-49 hours.

44% reported their ethnicity as white British and **20%** Black/African/Caribbean/Black British background.

29% had been caring for more than 15 years; **24%** had been caring for 8-15 years and **24%** for 1-3 years.

28% were aged 45-54 and **24%** 55-64 years old.

- **Change in the need for support from social care or health services**

10% said they needed less support with **10%** needing more. **40%** said there was no change.

- **Helpfulness of support**

Haringey

The following are different types of support you might have received from Carers First. For each one, please tell us how helpful you feel it was for you.
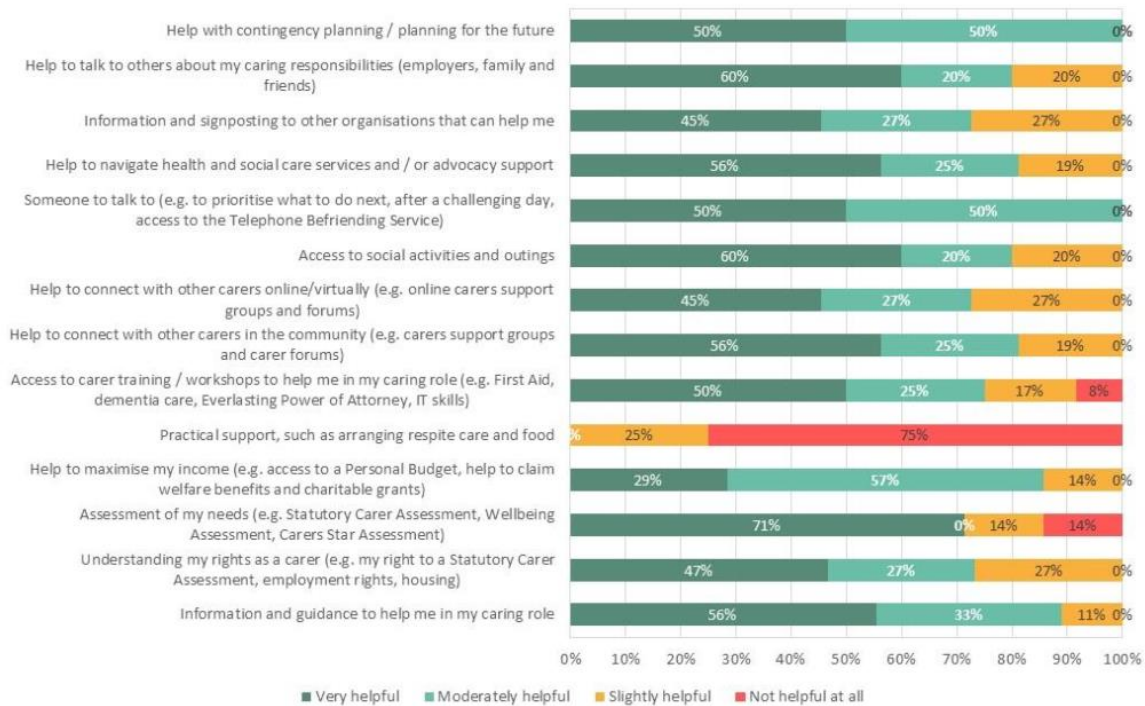
Support type	Very helpful	Moderately helpful	Slightly helpful	Not helpful at all
Help with contingency planning / planning for the future	50%	50%		0%
Help to talk to others about my caring responsibilities (employers, family and friends)	60%	20%	20%	0%
Information and signposting to other organisations that can help me	45%	27%	27%	0%
Help to navigate health and social care services and / or advocacy support	56%	25%	19%	0%
Someone to talk to (e.g. to prioritise what to do next, after a challenging day, access to the Telephone Befriending Service)	50%	50%		0%
Access to social activities and outings	60%	20%	20%	0%
Help to connect with other carers online/virtually (e.g. online carers support groups and forums)	45%	27%	27%	0%
Help to connect with other carers in the community (e.g. carers support groups and carer forums)	56%	25%	19%	0%
Access to carer training / workshops to help me in my caring role (e.g. First Aid, dementia care, Everlasting Power of Attorney, IT skills)	50%	25%	17%	8%
Practical support, such as arranging respite care and food		25%	75%	
Help to maximise my income (e.g. access to a Personal Budget, help to claim welfare benefits and charitable grants)	29%	57%	14%	0%
Assessment of my needs (e.g. Statutory Carer Assessment, Wellbeing Assessment, Carers Star Assessment)	71%	0%	14%	14%
Understanding my rights as a carer (e.g. my right to a Statutory Carer Assessment, employment rights, housing)	47%	27%	27%	0%
Information and guidance to help me in my caring role	56%	33%	11%	0%

Very helpful ■ Moderately helpful ■ Slightly helpful ■ Not helpful at all

Figure A10: Helpfulness of support - Haringey (n=21)

- **Impact of support received**

Carers rated the following as the difference the support made to them: **62%** are more aware of the support available if they need it and **48%** feel more connected with other people. **38%** felt better emotionally.

Haringey

Thinking about all of the support you've received from Carers First in the past, what difference do you feel it has made for you in your caring role?
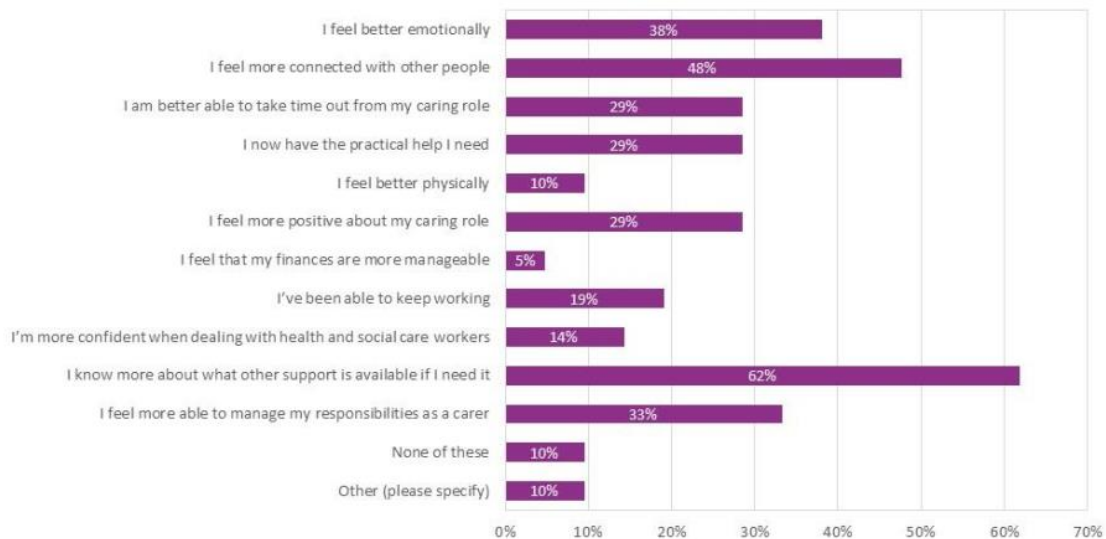
Category	Percentage
I feel better emotionally	38%
I feel more connected with other people	48%
I am better able to take time out from my caring role	29%
I now have the practical help I need	29%
I feel better physically	10%
I feel more positive about my caring role	29%
I feel that my finances are more manageable	5%
I've been able to keep working	19%
I'm more confident when dealing with health and social care workers	14%
I know more about what other support is available if I need it	62%
I feel more able to manage my responsibilities as a carer	33%
None of these	10%
Other (please specify)	10%

Figure A17: Impact of support received - Haringey (n=21)

- **Why carers seek help**

62% felt like they needed to talk to someone who understood their situation. **57%** sought support because their caring role was becoming more of a challenge and **57%** wanted to better understand the support available to them**.**

- **Why carers don't seek help**

44% of carers said they didn't have time to look; **22%** didn't see themselves as a carer and **22%** didn't realise help was available for someone in their situation.

Appendix B

Carers survey questions

1. Are you male or female?
2. Age?
3. Ethnicity
4. Have you received support with your caring role?
5. Did you receive all the support you needed?
6. Do carers from all backgrounds and cultures receive enough support?
7. We know that not all carers ask for help. Why do you think that is?
8. What would be really helpful for carers in Haringey?
9. How can we improve services for carers in Haringey?
10. Is there anything else that you would like to say about being a carer in Haringey?

Appendix C

Organisations who responded to the survey

North East Haringey PCN (Social Prescriber)

YOYO

Vibrance/HAIL

Haringey Memory Service

Alzheimer's Society

Centre 404

Haringey Over 50s Forum

North London Hospice

Citizens Advice Bureau

Adfam

Carers First

Whittington Health

Public Voice

Appendix D

Questions for organisations

1. Name of organisation
2. Name of person completing survey
3. How does your organisation support carers?
4. Does your organisation support a specific group of carers?
5. Are you aware of any inequalities? For example, are there any groups of carers who are not accessing services because of disadvantage or other reasons?
6. We know that not all carers ask for help. Why do you think that is?
7. Do you collect data to demonstrate the diversity of the carers and clients that you support? And if so, would you be willing to share it?
8. What would be really helpful for carers in Haringey?
9. How can we improve services for carers in Haringey?
10. Is there anything else you would like to say about being a carer in Haringey?

This report was commissioned by Haringey Council and written by Carers First

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