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1 Carers

1.1 Introduction

This section covers the health and wellbeing needs of informal carers in Hackney and the City. It does not cover professional ‘care workers’ who are employed to provide caring support for others.

An informal carer includes any person – such as a family member, friend or neighbour – who is giving regular, ongoing assistance to another person without payment for the care given.¹ Some of the support provided by friends and family can be seen as part of the routine way in which people form relationships, which can make it difficult to identify when a person is termed a ‘carer’.

In the UK, around 6.5m people are informal carers, and this is estimated to save the economy £132bn per year. [1] The last Census (2011) showed that the number of carers is increasing over time, particularly in people who care for more than 50 hours per week. The increase in the number of carers is attributed to the increase in life expectancy, and is also affected by the number of people living with (multiple) limiting and long-term health conditions. [2] [3]

The health and wellbeing of carers is an important area of social policy as it directly affects the supply of care required from statutory services, as well having the potential to have an impact on the quality of life and employment opportunities for those providing care. [4]

Box 1: Definitions used in this section

Adult carers – adults who are caring for other adults (usually a family member or friend), and adults who have caring responsibilities for a child they are not parenting. [5]

Parent carers – adults with a parental role for a child who has additional caring needs.

Young carers – children and young people under the age of 18 who care for others (usually family members). Young carers are outside the scope of this JSNA chapter, but are covered in the ‘Children and young people’ JSNA chapter.

1.2 Health and wellbeing impacts

As described in the introduction, informal carers make a significant contribution to supporting the health of vulnerable people, as well as contributions to the wider economy.

However, caring responsibilities can be detrimental to a person’s health, with direct impacts including physical strain from lifting or as a result of disrupted sleep patterns. Caring can also have an indirect effect on a person’s ability to maintain and support their own health and wellbeing – for example, caring for another person can change behaviour, which can result in poor diet, lack of exercise and increased stress. [6] [7] [8]

¹ Informal carers may be in receipt of Carer’s Allowance, which is money (provided by central government) to support people in their caring role. This is not the same as being paid to provide care to others as a ‘care worker’ in a professional capacity.

A survey of 3,400 carers nationally found over half (53%) had a long-term condition or illness, and more than a quarter (28%) stated they had a physical disability. The majority reported that caring had a negative impact on their physical health (83% of respondents) and mental health (87% of respondents). [3] Caring responsibilities can also affect education and employment potential, with 37% of respondents to this same survey (aged 18 to 64) reporting that they had ceased working because of their caring responsibilities. [3]. Other evidence points to an increased risk of specific conditions – for example, there is a 23% increased risk of stroke for spousal carers. [8]

The links between caring and physical health may be partly explained by delayed medical treatment – 39% of carers responding to the national survey described above reported that they had put off seeking medical treatment because of caring responsibilities. [3]

As well as physical poor health, 57% of carers report having a mental health condition such as anxiety or depression. [3] The suicide risk among carers is three times the national average. [9] However, there is some evidence to suggest that caring can have positive effects on satisfaction and self-esteem, which is likely to have a positive impact on some aspects of mental wellbeing. [10]

It is important to note here that the health and wellbeing impacts of caring are likely to vary for different types of people. Older carers, those from lower socio-economic groups and those with limited support networks report poorer psychological and physical health than carers who are younger and have more economic and interpersonal resources. [11]

1.3 Local data and unmet need

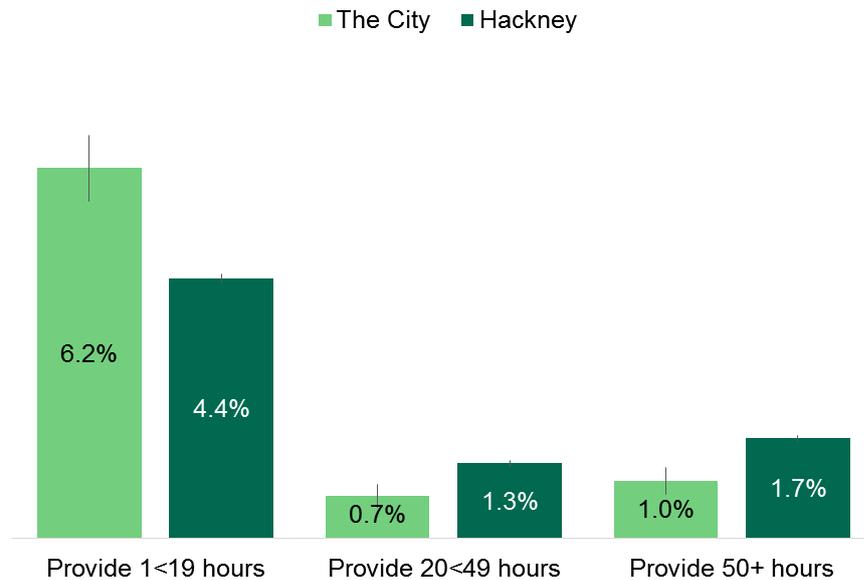
Local data are presented here on the number and characteristics of carers in Hackney and the City, from a number of different sources, each with its own limitations. Data are also presented on the health and wellbeing of local carers.

1.3.1 Number of informal carers and patterns of caring

Data on informal carers are available from the last Census, which was seven years' old at the time of writing. Moreover, data are not available for adults only. This source shows that, in 2011, 7.9% of City of London residents (all ages) and 7.3% of Hackney residents (all ages) were providing some level of unpaid care to a family member, friend or neighbour.

Applying these rates to the 2017 projected adult (18+) population, this equates to an estimated 506 adult carers in the City of London and 15,629 in Hackney. Most commonly, in the 2011 Census, people were providing under 20 hours of care a week, with longer hours more commonly reported among Hackney residents compared with City residents (Figure 1).

Figure 1: Percentage of residents in Hackney and the City providing unpaid care, by number of hours of caring per week (all ages, 2011)



Source: Office for National Statistics Census 2011. [12]

Note: The 2011 Census included the question 'Do you look after, or give and help or support to family members, friends, neighbours or other because of either; a long-term physical or mental ill-health/disability; or problems relating to old age?'

1.3.2 Number of carers receiving support

Primary care (GP) data

GP systems are not routinely used to record or monitor the number of people who provide unpaid care. While a 'carer' code is available to use by GPs, no coding criteria are defined, which means there is potential for practitioners to interpret and use this code in different ways. The primary care data presented in this section therefore should be treated with some caution.

With the above caveats in mind, 1.7% of adults (age 18+) in Hackney and the City are recorded by their GP as a 'carer' – 4,172 people in total. [13]

Social care data

Social care data provide information on the number of carers who access support from a local authority.

Statutory reporting identified 1,160 adult (age 18+) carers in Hackney in 2015/16, representing 0.6% of the adult resident population.² During this same year, 1,255 episodes of 'carer support' were delivered by Hackney Council's social care team.

² Routine reporting uses numbers rounded to the nearest five. [18]

An individual can receive more than one ‘episode’ of support. A preliminary analysis of social care records in Hackney 2016/17 showed 1,341 episodes of ‘carer support’ were delivered during the year. [13] [14]

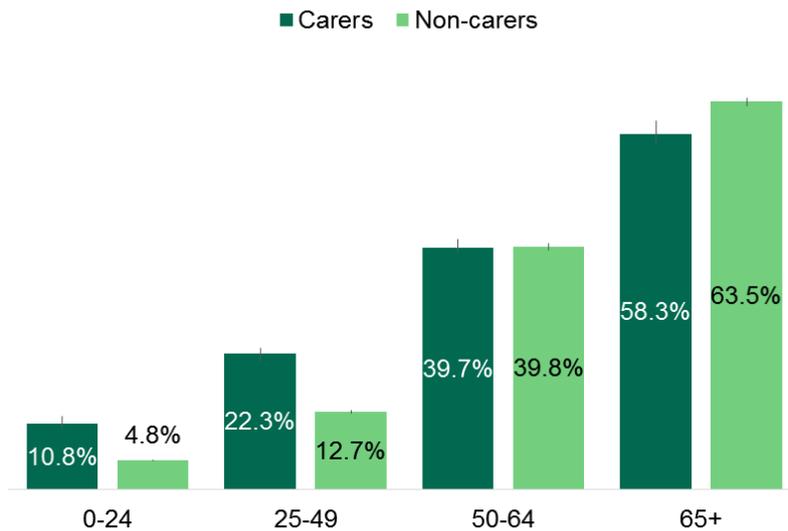
In the City of London, 53 carers were known to adult social care during 2015/16. [15]

1.3.3 Health and wellbeing of carers

Census data (2011)

Data from the 2011 Census indicate the relatively poor health status of people with caring responsibilities, especially in younger age groups (see Figure 2 below).

Figure 2: Proportion of Hackney and the City residents with self-reported fair, bad or very bad health (2011)

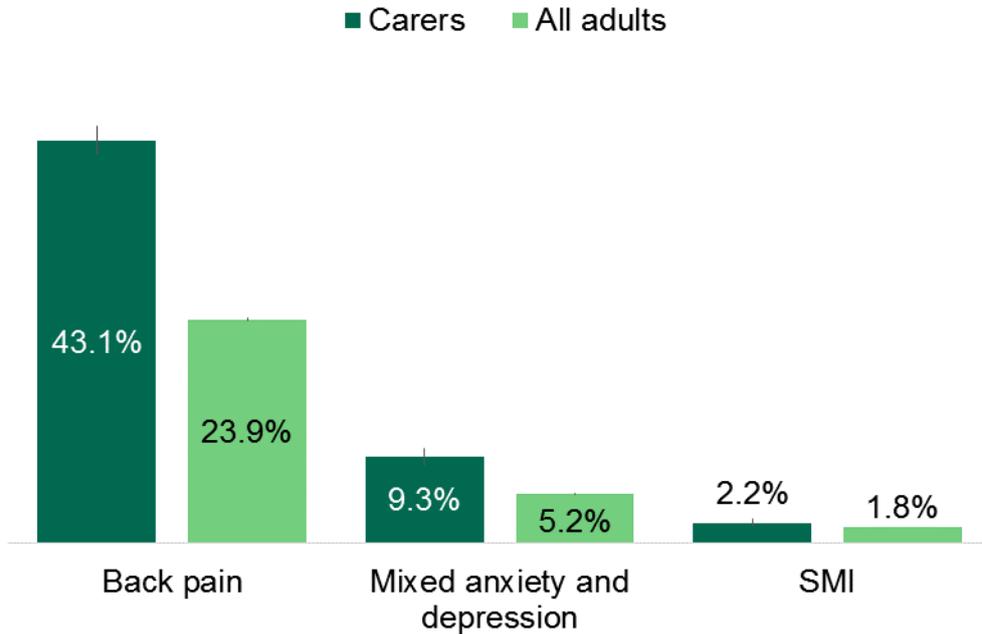


Source: Office for National Statistics (ONS) Census 2011. [4]

Primary care (GP) data

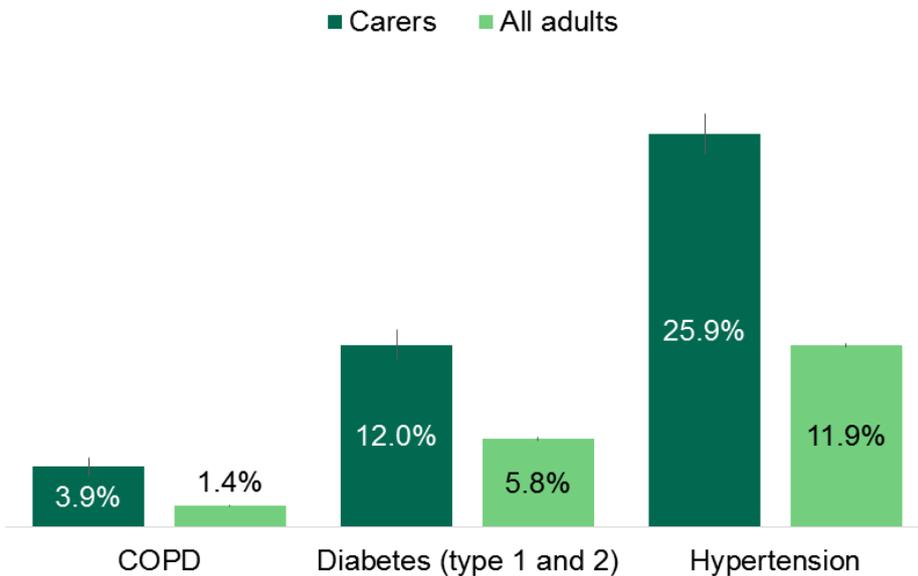
Using data from local GP records, Figure 3 and Figure 4 confirm that adult carers (identified to their GP) are much more likely to experience a range of specific health conditions than average – rates of back pain, chronic obstructive pulmonary disease (COPD), diabetes and hypertension are all close to double that of the total adult patient population.

Figure 3: Prevalence of GP-recorded back pain, mixed anxiety and depression and serious mental illness (SMI) in Hackney and the City residents (18+, 2017)



Source: Extracted from the local GP register by Clinical Effectiveness Group (CEG), Blizard Institute, April 2017. Data cover residents of Hackney and the City registered with a GP in Hackney, the City of London, Tower Hamlets and Newham.

Figure 4: Prevalence of GP-recorded COPD, diabetes (type 1 and 2) and hypertension in Hackney and the City residents (18+, 2017)



Source: Extracted from the local GP register by Clinical Effectiveness Group (CEG), Blizard Institute, April 2017. Data cover residents of Hackney and the City registered with a GP in Hackney, the City of London, Tower Hamlets and Newham.

Carers' survey

The Carer's Survey is a biennial national survey³ of adult carers who receive support from local authorities. This provides another source of data on the health and wellbeing needs of carers. The latest survey (in 2016/17) includes a sample of 312 people in Hackney who were in receipt of carer support from adult social care. Due to low numbers and data access issues, a detailed analysis of survey data for the City has not been possible, but, where available, relevant survey results are reported below.

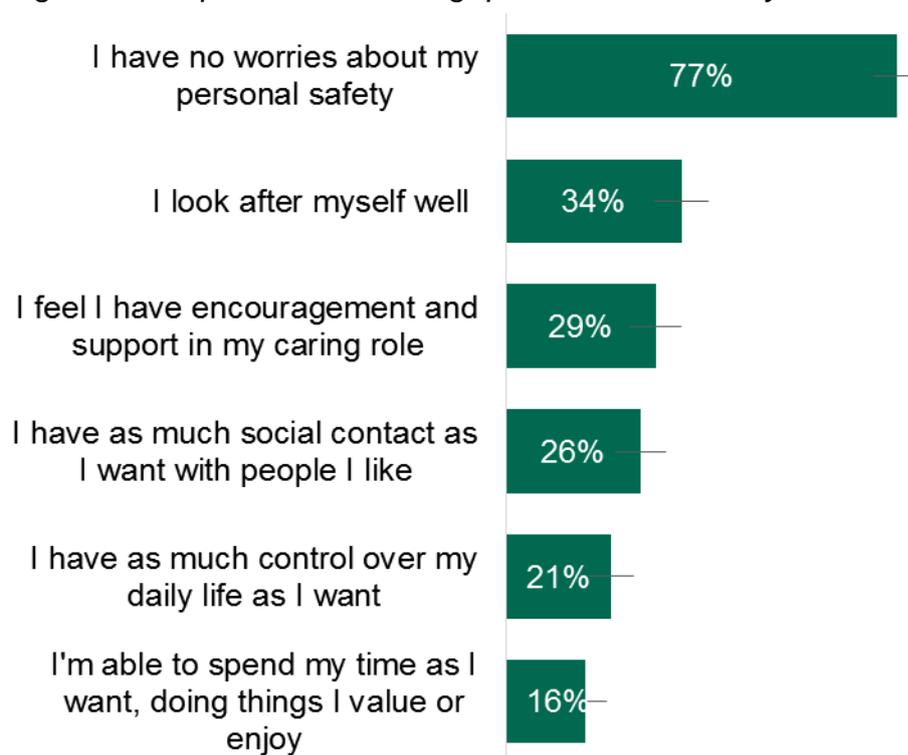
Hackney respondents to the survey have relatively high and long-term caring responsibilities. Three quarters of respondents had been caring for someone for over five years, and two thirds routinely provided over 35 hours of care per week.

A carer's quality of life is measured in this survey using a score out of 12, based on responses to six questions relating to occupation, control, personal care, safety, social participation and support. Using this aggregate measure, and based on a provisional analysis of the data, Hackney carers scored an average of 6.9 (out of 12) for quality of life in 2016/17, with the average score falling over time (since 2012/13). [16] Carers in the City of London had a higher average quality of life score in 2016/17, of 7.7. [15]

Figure 5 below reports responses to wellbeing-related questions from Hackney respondents to the Carers' Survey. Only a quarter (26%) of Hackney carers stated that they felt they had as much social contact as they would like, and just a third (34%) stated they felt they were able to look after themselves 'well'. Only a small minority (16%) felt they were able to spend time doing things they enjoy. Results for the City of London (not presented here due to small numbers) were broadly similar to Hackney.

³ The survey is administrated by NHS Digital but delivered locally. The results form part of the Adult Social Care Outcomes Framework (ASCOF).

Figure 5: Response to wellbeing questions in Hackney carers' survey (18+, 2016/17)



Source: Hackney performance team, data from *Hackney carers' survey*. [16]

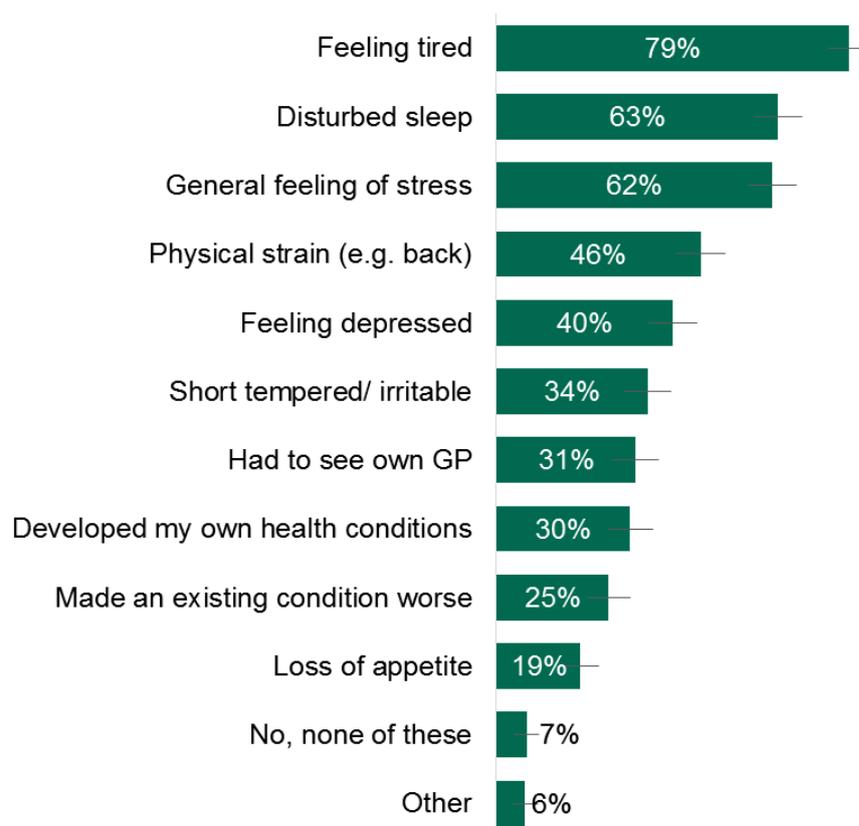
Note: Specific questions asked:

- Thinking about your personal safety, which of the statements best describes your present situation?
- Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?
- Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?
- Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?
- Which of the following statements best describes how much control you have over your daily life?
- Which of the following statements best describes how you spend your time?

Hackney carers responding to the survey also reported a range of health impacts of caring, with tiredness and disrupted sleep being the most common (see Figure 6). In addition, echoing the primary care data presented earlier, two out of every three (60%) Hackney carers reported having a specific health condition.⁴ A similar proportion (66%) stated they had some level of financial difficulty in the past 12 months due to their caring role.

⁴ Specific health conditions asked about include: a physical impairment or disability; sight or hearing loss; mental health problem or illness; a learning disability or difficulty; a long-standing illness; other.

Figure 6: Health effects of caring role reported in Hackney carers' survey (18+, 2016/17)



Source: Hackney performance team, data from *Hackney carers' survey*. [16]

1.3.4 Unmet need

Due to data limitations, it is not possible to make a reliable assessment of the level of unmet need in relation to carers' health and wellbeing in Hackney and the City of London. However, it is reasonable to assume that nationally reported findings of high levels of unmet need apply locally. [3]

Only a small percentage of carers request or receive a formal assessment from their local authority and, therefore, many are unlikely to be in receipt of the support that they need.

1.4 Inequalities

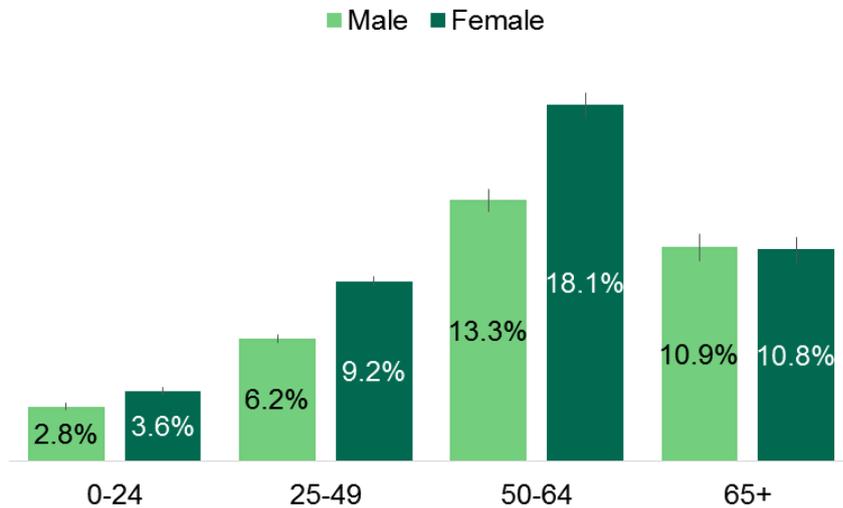
Data in this section are combined for both Hackney and the City of London.

1.4.1 Age and gender

The likelihood of being a carer varies with both age and gender.

Figure 7 shows that the proportion of the population who provide unpaid care increases with age up to 64 years, and then decreases among those aged 65+. Under the age of 65, women are more likely to provide unpaid care than men.

Figure 7: Percentage of residents in Hackney and the City providing unpaid care, by age and gender (all ages, 2011)

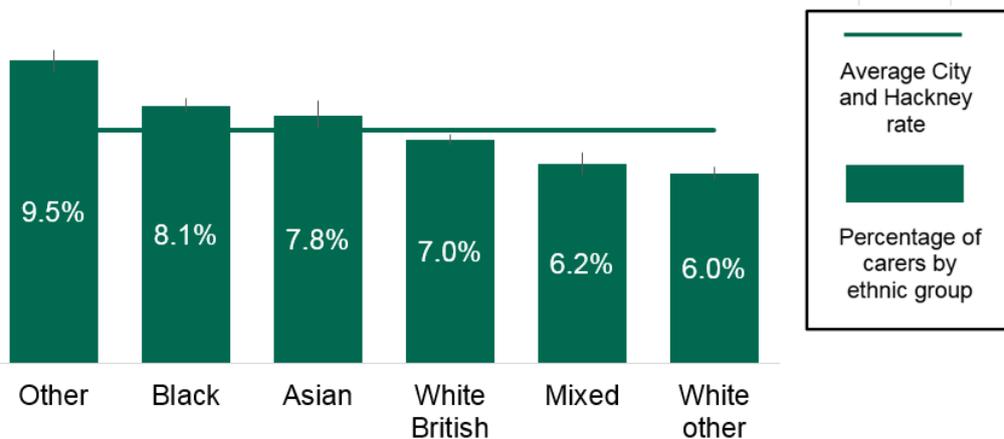


Source: Office for National Statistics Census 2011. [4]

1.4.2 Ethnicity

Census data on caring status by ethnicity are not available broken down by age, and so the available data may mask differences that are (partially) explained by differing age profiles of different ethnic groups. The data that are available show that, in Hackney and the City, people of Black and Other ethnicity are more likely to provide unpaid care than average; White British, White Other and Mixed residents are less likely to do so (Figure 8).

Figure 8: Percentage of residents in Hackney and the City providing unpaid care, by ethnicity (all ages, 2011)



Source: Office for National Statistics Census 2011. [4]

1.4.3 Disability

As described in Section 1.3.3, there are higher rates of self-reported physical and mental health conditions among carers than the total population.

1.4.4 Socio-economic disadvantage

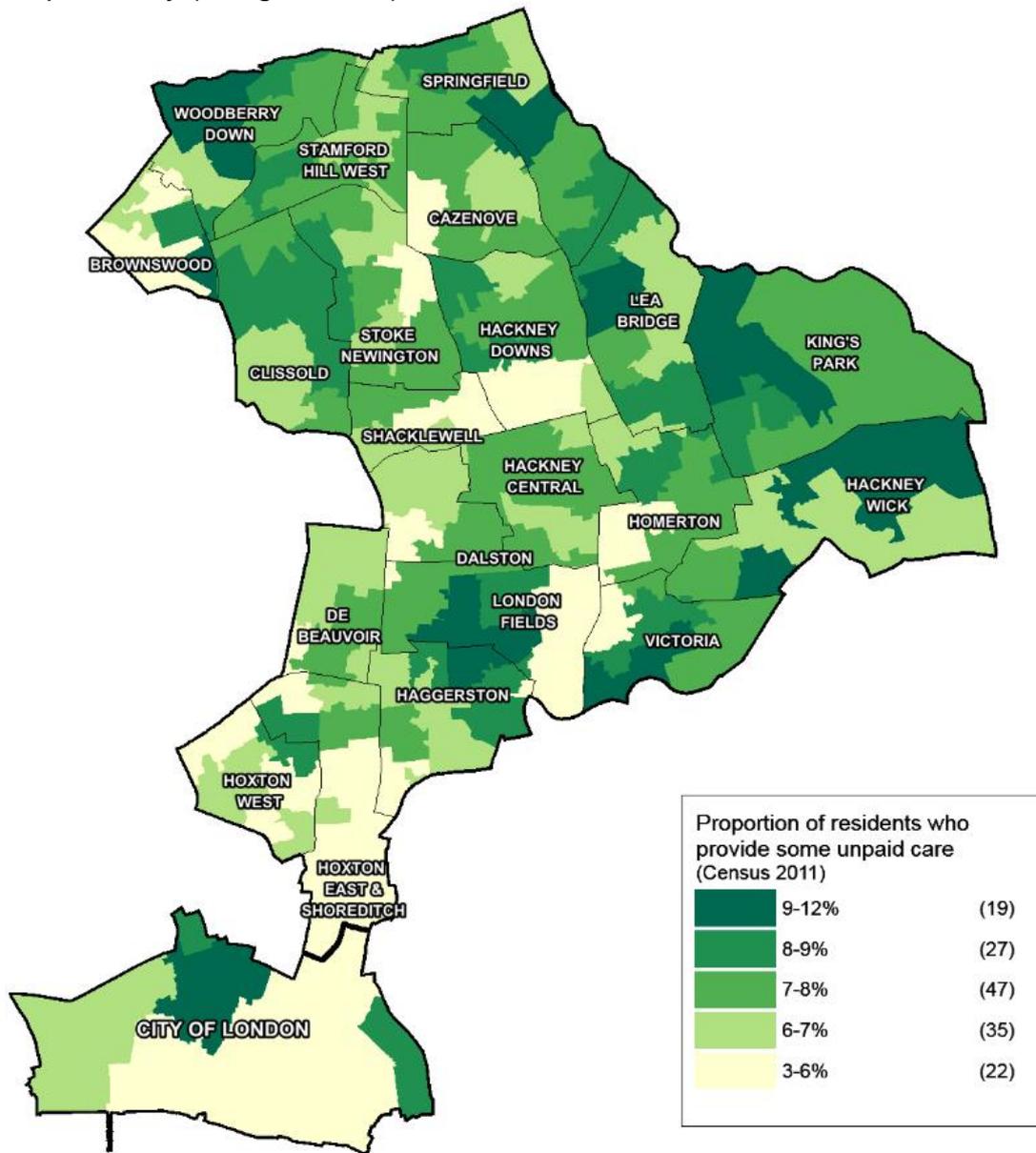
Local Census data point to a small, but positive, relationship between local area deprivation (defined using the Index of Multiple Deprivation) and the percentage of residents with caring responsibilities in Hackney and the City.⁵ [4]

1.4.1 Location within Hackney and the City

In Hackney, the areas with 9–11% of the population providing unpaid care are mainly in the east of the borough (Hackney Wick, King's Park and Lea Bridge). The City of London has a higher prevalence of carers in the north, in and around the Barbican estate (Figure 9).

⁵ The Index of Multiple Deprivation (IMD) is a single measure that combines indicators across seven domains (income; employment; health and disability; education, skills and training; barriers to housing; crime; and living environment) to provide an overall measure of deprivation for each area, relative to other areas within England.

Figure 9: Percentage of the Hackney and the City population with a caring responsibility (all ages, 2011)

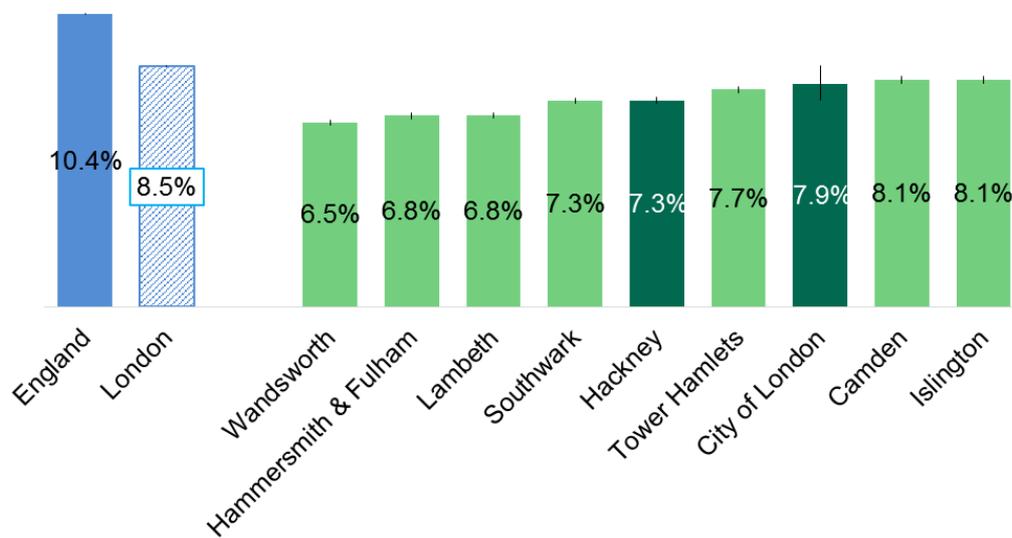


Source: Office for National Statistics Census 2011. [4]

1.5 Comparisons with other areas and over time

The percentage of the Hackney and City of London populations that provide unpaid care to friends, family or neighbours appears lower than the London and England rates, but among the highest of Hackney’s statistical peers.

Figure 10: Percentage of population that provide unpaid care (2011)



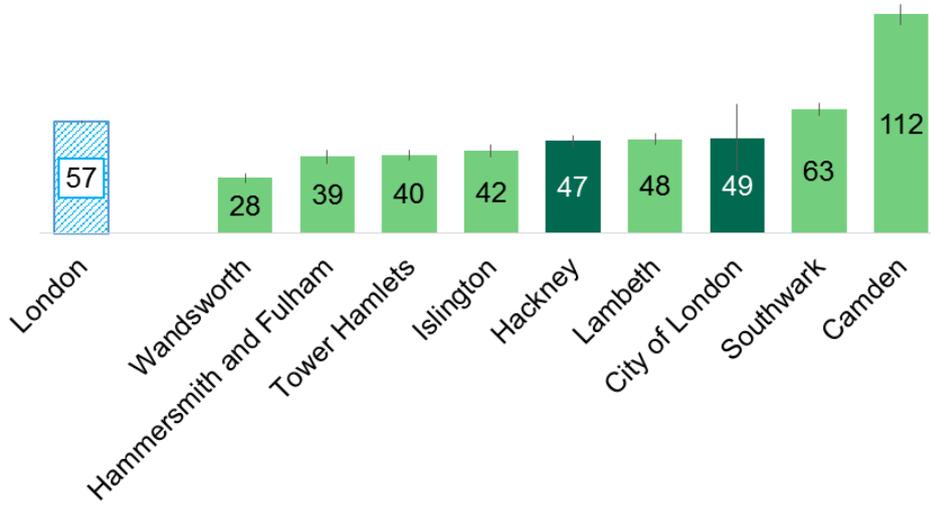
Source: Office for National Statistics Census 2011. [4]

Receipt of support for carers (per 100,000 population) is lower in Hackney and the City of London than the London average (Figure 11 and Figure 12). Rates of support in Hackney are in line with most similar areas for working-age adults (aged 18–64), but are at the higher end of the range for people aged 65–84 (Figure 11). There is a relatively small population of people aged 85+ in Hackney, and significantly fewer of them receive support for caring for others.

It is estimated that a higher proportion of adults aged 65+ live alone in Hackney (42%) than in London overall (35%), which might imply that spousal caring in older age groups is less likely in Hackney. [17]

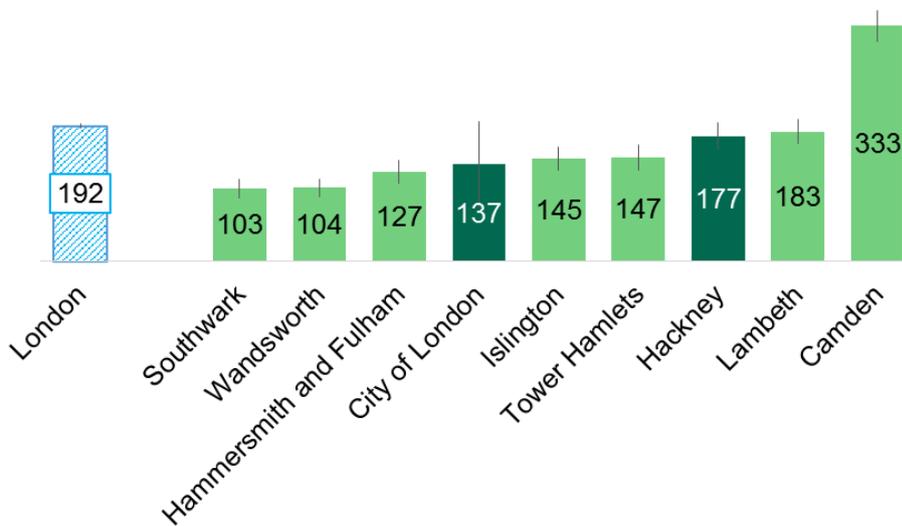
Due to small numbers, confidence intervals around the rates for the City of London reported in Figure 11 and Figure 12 are quite wide. The data suggest that rates of receipt of carer support (in both the 18–64 and 65–84 age groups) are similar to most of Hackney's statistical peers.

Figure 11: Adults receiving carer support (rate per 10,000 population, age 18–64, 2016/17)



Source: NHS Digital. [18]

Figure 12: Adults receiving carer support (rate per 10,000 population, age 65–84, 2016/17)



Source: NHS Digital. [18]

Between 2014/15 and 2016/17 there has been an 18% increase in the absolute number of requests made to Hackney Council for carer support. [16]

1.6 Evidence and good practice

1.6.1 Prevention of poor health and wellbeing

There is evidence that the physical and mental impact of caring can be mitigated or possibly prevented by providing practical and financial support to carers. In a national survey, when carers were asked about the factors they believe have affected their physical and mental health, two thirds (64%) identified a lack of practical support as being a contributing factor, and half (50%) stated that a lack of financial support had had an impact. [3]

There is also likely to be an important role for health professionals. In the same national survey, four in five (84%) carers reported that they were known to their GP, but only a quarter (23%) reported having been offered a health check by their GP. [3] Additionally, two thirds (66%) of carers felt that health professionals do not signpost them to information of support. Charities and support groups were identified as the main providers of this information. [19]

1.6.2 Identification and early intervention

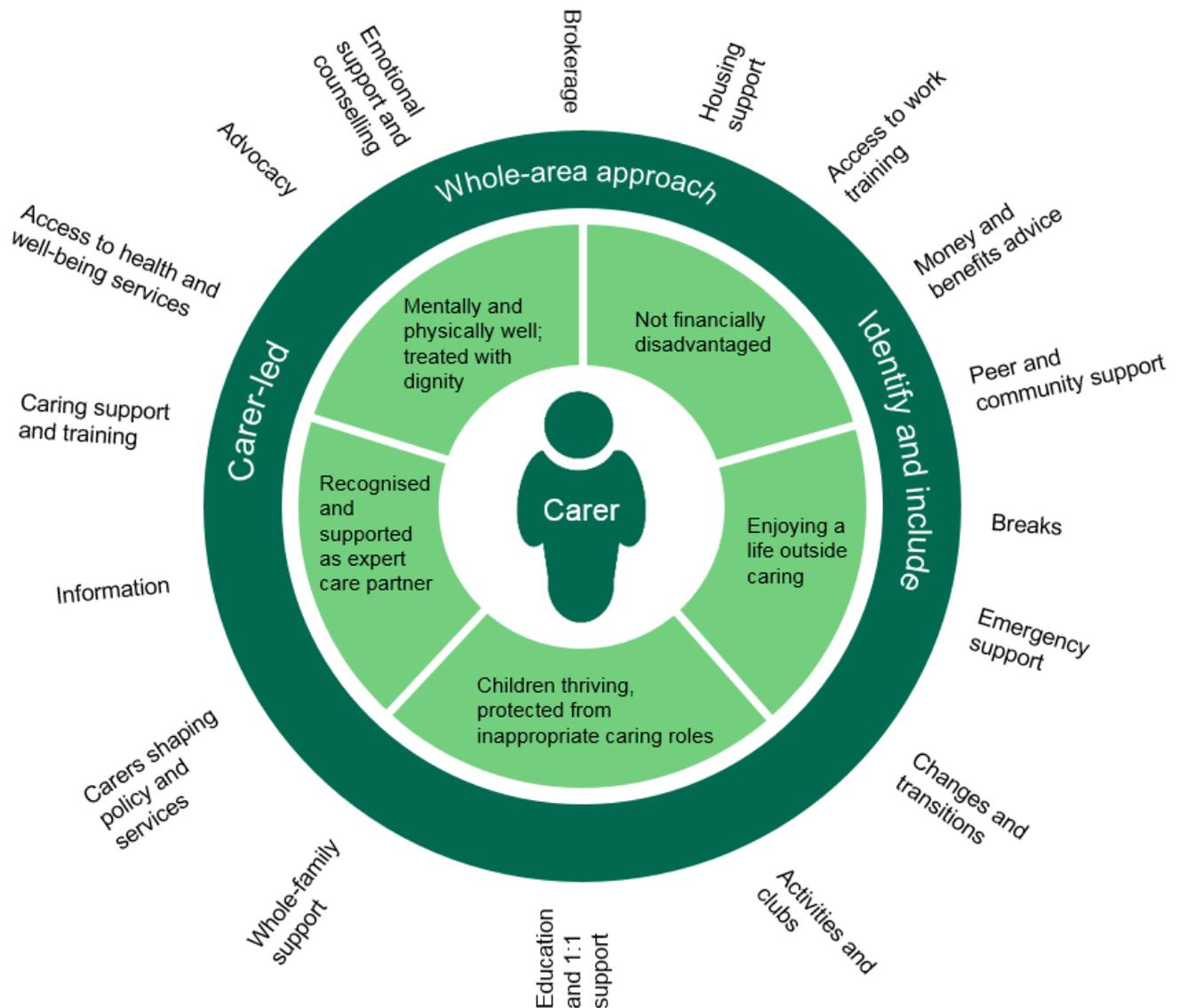
Early intervention and provision of support to carers should be a priority, and the timing of appropriate interventions for carers has been emphasised in a number of settings. [20] However, some research has struggled to identify a specific moment or window at which support programmes should be offered. [21] The diverse experiences and support requirements of carers mean that early intervention should be prioritised, but the approach should be person-centred and respond to differing needs.

It should also be noted that early identification and intervention may present challenges, as individuals often do not identify or define themselves as carers. Rather, they may see their role as a spouse, sibling, son/daughter or friend. This can mean carers are less likely to seek out formal support, and that there is a greater need for services to proactively identify carers to meet their needs. [22] There may be a particular opportunity for health professionals, including GPs, to support this. Proactive identification and intervention to support carers is likely to be particularly beneficial for those at higher risk of poor physical and mental health, as outlined in Section 1.2.

1.6.3 Treatment, care and support

There are a number of different needs that carers may have, expressed in the model of comprehensive carer support below (Figure 13). [23] This captures the range of different support that should be offered, and the outcomes that these contribute to.

Figure 13: A model of comprehensive carer support (2010)



Source: ADASS, Carers UK, Crossroads Caring for Carers, IDeA and LGA. [23]

Support for carers should include practical and financial support, as well as social support, which has been shown to have a substantial effect on carers' outcomes. Social support corresponds with fewer depressive symptoms and a reduced perception of the burden of caring responsibilities. Social support may also help carers to find out about local services and peer networks, helping to reduce the isolation and withdrawal that has been associated with caring. [20]

Avoidance as a coping strategy has been associated with depression in carers of children with autism and people with dementia. [24] [25] Conversely, coping strategies that are centred on empowerment, self-efficacy and confrontation (of problems or emotions) are believed to be worthwhile for carers. It has been recommended that support programmes should focus on these latter coping strategies, but that mainstream service provision does not always address these aspects. [26]

Overall, evaluations of the effectiveness of interventions that aim to provide support to carers have produced somewhat inconsistent results. This may be due to the numerous factors that can affect the impact that caring can have on an individual. [27] In addressing this, a multi-disciplinary approach is required that focuses on the numerous risk factors experienced by carers, as outlined in Figure 13. [20] [23]

The Care Act 2014 explicitly states that supporting individual wellbeing applies equally to carers as to those for whom they care. This element of the Act emphasises the importance and responsibility of local authorities.

Guidance is currently being produced by the National Institute for Health and Care Excellence (NICE) on provision of support for adult carers. This guidance is scheduled for publication in July 2019. [28]

1.7 Services and support available locally

Services to support carers locally are generally funded by the local authorities (Hackney Council and City of London Corporation) and City and Hackney Clinical Commissioning Group (CCG). Services are delivered by the local authorities and the NHS, plus a wide range of third sector organisations.

In early 2018 the Health in Hackney scrutiny commission investigated the current offer of support to carers in the borough. The findings revealed low carer satisfaction with local services over time, which is being addressed by Hackney Council through a redesign of the support offer. The report, with evidence and a full list of recommendations, is available through the Hackney Council website. [29]

1.7.1 Prevention of poor health and wellbeing

City and Hackney Carers Centre

City and Hackney Carers Centre was established to be the first point of contact for carers in the borough, providing advice, information, advocacy and support to unpaid carers. This includes counselling, life coaching, befriending and a range of support groups, as well as keeping in touch with carers via a quarterly newsletter. Part of the centre's role is to provide the Carers Coordination Service on behalf of the Carers are the Bedrock partnership (see below). A detailed description of services on offer to carers is available in the Health in Hackney scrutiny commission report available through the Hackney Council website. [29]

Services provided by City and Hackney Carers Centre include:

- carers groups, where carers can access peer support
- carer's assessments (see Section 1.7.2 for details)
- personalised and confidential advice in relation to housing needs, welfare rights/benefit checks, education and transport, plus information about social care services
- individual support offered via the Advocacy for All Hackney project
- a low-cost counselling service (using sliding-scale fees based on income)

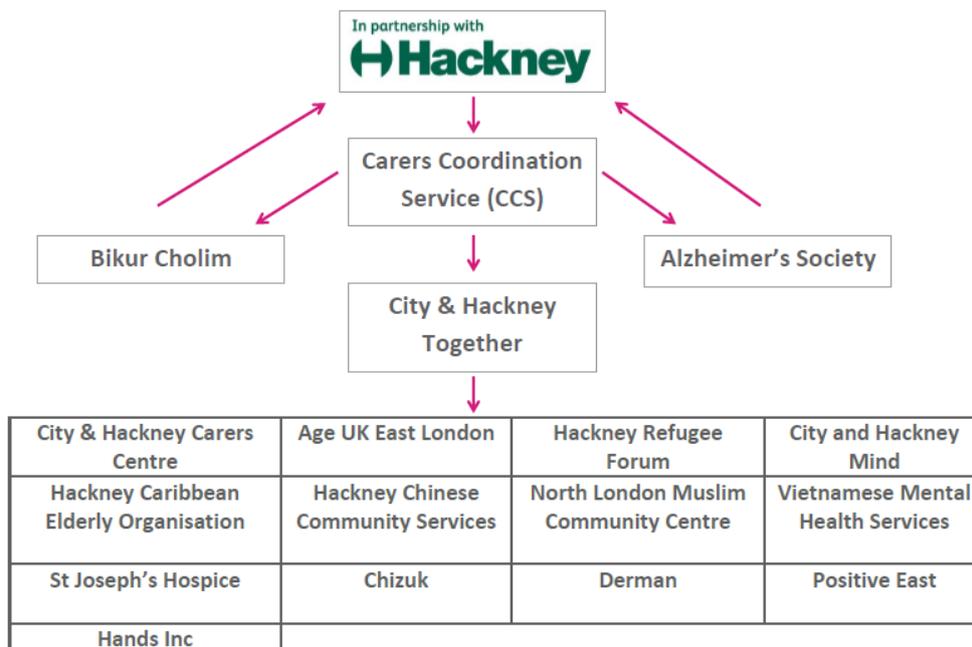
- Listening Ear service (providing a space for carers to share problems)
- Hackney carer’s card scheme
- coaching
- quarterly carer’s newsletter
- a range of training courses and events (including for Carers Week in June, and Carers Rights Day in November).

Carers are the Bedrock

Carers are the Bedrock (CATB) is the name of a partnership commissioned by Hackney Council and coordinated by City and Hackney Carers Centre. This network provides a link between partner organisations to enable carers to have greater choice about who undertakes their carer’s assessment (see Section 1.7.2). There are 13 voluntary sector providers involved in the partnership, with the bulk of assessments currently being carried out by five partner organisations (Mind, City and Hackney Carers Centre, Derman, Alzheimer’s Society and Bikur Cholim).

Each organisation within the partnership also provides personalised information, advice, signposting and services to carers. The Carers Coordination Service coordinates referrals across the partnership and submits assessments undertaken by partners to the local authority for sign-off. The structure of the partnership is shown in Figure 14 below.

Figure 14: Carers are the Bedrock partnership structure (2017)



City Carers Service

The City Carers Service has been created especially for informal carers resident in the City of London, in collaboration with the Carers Network (which also covers Westminster, Hammersmith, Fulham, Kensington and Chelsea). [30] The City Carers Service offers carers:

- a friendly, confidential listening ear – at home, over the phone, via Skype or email, or at a monthly drop-in
- help to navigate the maze of services, professionals or forms that many carers come across
- expert information and advice on carers' rights
- support to help carers find ways to manage their caring role, and to find a balance between caring responsibilities and other activities
- a chance for carers to meet and share experiences with each other at monthly support groups, and to hear from local professionals
- opportunities for training, social events, trips and activities.

The Carers Network has a dedicated website for the City Carers Service.

The City Carers Service is also a part of the Reach Out Network. This network is a collaboration between services working to reduce social isolation among City of London residents, while also encouraging residents to live and age well.

1.7.2 Identification and early intervention

In Hackney, the local authority's information and assessment (I&A) team deals with all enquiries regarding adult social care support and services for Hackney residents. The team provides information and advice, receives referrals for carers who are not already in receipt of services and completes initial contact assessments to determine the best means of supporting people. The I&A team can signpost referrals to other relevant teams or services as appropriate (e.g. sensory support, learning disabilities, mental health, occupational therapy), as well as signposting to other community-based services for local support.

Any carer with potential social care needs can contact the I&A team, who will then conduct the necessary assessment to determine eligibility for support.

In the City, people who provide unpaid care can make an enquiry to adult social care services, which will provide the appropriate contact and assessments to access appropriate support in the local area.

Carer's assessment

When someone provides, or intends to provide, care for another adult, and it appears they may have support needs of their own, local authorities have a duty to carry out a carer's assessment. In Hackney, this can be undertaken by a Hackney

Council social care professional, an East London NHS Foundation Trust (ELFT) healthcare professional or a carer's assessor from the Carers are the Bedrock (CATB) partnership.

The aim of the assessment is to establish the carer's need for support and their ability to sustain their caring role. Carers can receive an assessment jointly with the person they care for, or separately in their own right, and regardless of whether the person they care for has needs defined as eligible for social care support. Joint assessments with the person receiving care are undertaken by social care professionals.

There were 1,341 carer's assessments performed in Hackney, and 53 in the City of London, in 2016/17. Of all carer's assessments in Hackney, 559 (41%) were performed jointly with the cared-for person. [16]

As a result of the assessment, support services can be delivered directly to the carer or to the cared-for person, or may simply involve signposting to suitable local services. At least two thirds of people receiving a carer's assessment in Hackney receive some form of information, advice and signposting to other services.

1.7.3 Care and support for carers

Carer support plan

Following a carer's assessment, where eligible needs have been identified a support plan may be developed. This is a personalised plan, developed with the carer to support them to continue in their caring role. It sets out how their identified needs will be met, links back to the outcomes the carer wishes to achieve and should reflect the carer's aspirations, supporting them to balance their caring role alongside a life outside caring. The support plan should also reflect the carer's needs in relation to work, education, training or any leisure activity, in a way that is personalised to their needs and lifestyle. [31]

Respite and sitting services

Respite services (sometimes referred to as sitting services) are commonly sought by both carers and those they care for. These services may involve care being provided for someone at home or in a short-term residential placement.

Respite care is organised by social care professionals following a community care assessment of the cared-for person (which also involves assessment of the carer). When a short break is identified as being required, it will form part of the support plan of the cared-for person. Short-break (also known as replacement care) services are subject to financial assessment.

Carers requiring respite or sitting services can discuss this with their social worker or care coordinator, or call the relevant adult social care team (such as the: information

and assessment team; long-term team; community mental health (older people) team; or integrated learning disabilities team).

Carer's Allowance

Carer's Allowance is a payment (of up to £62.70) from central government for any person (age 16+) who meets the eligibility criteria, including providing at least 35 hours of care per week. A person's eligibility to, and the specific value of, the payment depends on whether the cared-for person is also in receipt of certain disability benefit payments. Further information on Carer's Allowance is available online from the Department for Work and Pensions.⁶

In May 2017, around 3,700 adults were receiving Carer's Allowance in Hackney and 30 people from the City of London.⁷ [32]

Carer's direct payment

Following a carer's assessment, carers with eligible needs may receive a personal budget. This may be for an ongoing service or paid as a one-off carer's direct payment. The amount allocated depends on eligible needs identified in the assessment, and any payment is allocated for carers to spend in an agreed way that helps sustain them in their caring role and seeks to maintain their health and wellbeing.

There were 506 direct payments made by Hackney Council to carers in 2016/17, of which 40% were for short breaks and 37% were for purchasing items to support their caring role (such as household appliances or technology) – see Figure 15. [16]

The City of London issued 53 direct payments to carers in 2016/17. [15]

⁶ <https://www.gov.uk/carers-allowance>

⁷ Note numbers are rounded to the nearest 10.

Figure 15: Percentage of carer's direct payments issued in Hackney, by description of payment type (2016/17)



Source: Hackney performance team. [16]

Hackney carer's card

Carers aged 18 or over who provide care for a Hackney resident (of any age) can apply for a Hackney carer's card. The card enables carers to receive discounts on goods in some local retailers, and also leisure centres and alternative therapists. Carers can contact City and Hackney Carers Centre to access this scheme.

1.8 References

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