

# Research on Carers within Seldom-Heard Communities: Final Report

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# Executive Summary

## Research methodology and the respondents

1. The aims of this study were to investigate the obstacles to carers gaining access to public services and to determine what types of services and resources can help them to fulfil their role and maintain their own well-being.
2. The study adopted a qualitative approach to the research, using a semi-structured questionnaire to gather data from 40 seldom-heard carers and 11 stakeholders (service providers and community leaders). The fieldwork for the project was carried out between 25 July and 5 November 2016.
3. The seldom-heard carer groups include black and minority ethnic (BME) communities; new migrants/asylum seekers; those who support people misusing substances, suffering from mental health problems, and experiencing impaired hearing; young carers; carers in rural/isolated areas; gypsies and traveller communities; ex-forces veterans; the lesbian, gay, bisexual and trans-sexual community; and those who support people who have acquired brain/head injuries.
4. Of the 40 carers interviewed, 30 were female and 10 were male. 27 respondents were 'White', four were 'Black/Black British', four 'Asian/Asian British', two 'Chinese', two 'Gypsies' and one was 'mixed'.
5. Nine people receiving care had one health problem, 17 had between two and three health problems and 14 had four or more health problems.
6. 47.5 per cent of respondents had been providing care for a period between 5 and 14 years and 20 per cent of respondents had been undertaking caring duties for more than 15 years.
7. Five per cent of respondents had undertaken between 50 and 99 caring hours per week and 37.5 per cent of respondents had typically undertaken more than 100 hours.
8. 47.5 per cent of respondents were carrying out 10 or more items of care listed in the questionnaire and 30 per cent respondents were carrying out between six and nine items of care.

## The concept of carer

9. Nearly all respondent carers believed that it was their duty to take care of family members.
10. The perception of caring among BME respondents has been shaped by culture. Asian and African carers tend to live with parents and take care of them.

11. Service providers said that the term 'carer' was a barrier to them communicating effectively with service users. They emphasised that taking on the role of carer was a gradual process and that people being cared for might feel ashamed about being a burden to family members, if those who were looking after them were labelled a 'carer'.
12. It was suggested that the phrase 'looking after someone' would be a more effective way of facilitating the relationship between service providers and service users.
13. Of the 40 respondents, 27.5 per cent had one health problem, 20 per cent had between two and three health problems and 7.5 per cent had more than four health problems.
14. Most respondents said that the caring duties they undertook drained them of energy so that they felt tired, exhausted and stressed.

### **Caring duties and impact**

15. Owing to demanding caring tasks and the unpredictable behaviour of those for whom they were caring, some respondents claimed that they experienced problems sleeping and that their mental health had deteriorated.
16. 'Loneliness and isolation' was the most common feeling among the respondents. The social and leisure time of most respondents was restricted by their caring duties; they had little time to meet relatives and friends.
17. Respondents' caring obligations had affected their job choices and work arrangements. Some respondents worked only part-time because it was the only way to balance the demands of work and their caring duties. Other respondents had decided to give up their jobs altogether in order to fulfil their caring commitments.
18. Carers who had little savings and relied on social security benefits as their only source of income had to manage a very tight budget, particularly if they had children. Respondents who had to give up their jobs in order to meet their caring commitments faced a reduced income and even financial hardship.

### **Sources of support and carer's assessment**

19. Respondents who were born in the UK could obtain support from close relatives; they also sought support from various types of health and social care organisation.
20. By contrast, respondents from minority ethnic communities mainly used NHS services, and sought advice from family members and ethnic and religious associations. Both service providers and community leaders emphasised that language was the biggest barrier to respondents gaining access to public services.

21. Of the 39 valid responses, 29 respondents had heard about a carer's assessment and nearly 70 per cent (20) of them had undertaken it.
22. There was mixed feedback on the carer's assessment. Some respondents understood the benefits of the carer's assessment and undertook it; others had little understanding of the assessment and also confused it with other types of assessment. From the observations of stakeholders, it appeared that some service users might have heard about it but had limited understanding of its content. Fear of contacting statutory organisations, a strong self-help culture, stigmatisation associated with certain health problems and language barriers meant that their motivation for undertaking it was relatively low.

### **Recommendations**

23. The findings of this study have generated several recommendations for improving services for carers.
24. Both respondent carers and stakeholders mentioned the essential role that GP surgeries play in helping carers to understand their needs and in signposting to suitable support services. The role of community and religious organisations in supporting carers and connecting them to public services was widely recognised by the respondents.
25. As the term 'carer' does not reflect the actual experience of service users and also creates an uncomfortable relationship between service users and frontline workers, it is proposed that the County Council use a more appropriate and sensitive term in its service and promotion materials in the future.
26. Currently, there is a division of responsibility between two different carer organisations and some carers have to contact two organisations in order to obtain assistance. It is proposed that Nottinghamshire County Council consider whether or not to provide a streamlined service through a single organisation establishing a single point of contact for carers seeking assistance.
27. A significant number of carers experience stress, loneliness and deterioration in their mental health; therefore, it is recommended that workers need to receive appropriate training to support carers.
28. There is potential for communication barriers to exist between informal carers from minority and ethnic communities and care workers. Hence, the Council and its partner organisations should consider recruiting more care workers who can speak English and other languages so that it can offer more culturally sensitive support to BME service users.
29. There is a need to revise the scheduling of support groups in order to fit the employment patterns of carers. Support groups also need to give support to carers to release them from work to attend meetings.
30. Some carers' problems are relatively complicated, and require special knowledge and the involvement of various professionals for their

resolution – for example, those who are looking after someone who has alcohol and drug problems. Relevant funding bodies should support, jointly, specialist organisations to offer effective services for this group of carers.

31. One respondent pointed out that the current short-term funding approach impedes the development of social service agencies. Service providers have to spend a lot of time preparing grant submissions, with the consequence that they have less time to spend providing direct services. Therefore, funding organisations need to minimise the use of a short-term approach to funding.

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# 1. Introduction

The needs of informal carers have become one of the major welfare concerns in recent years. In particular, following the introduction of the Care Act (2014), all informal carers are entitled to a carer's assessment, regardless of income and whether or not they are receiving local council services. The assessment aims to address

(a) whether the carer is able, and is likely to continue to be able, to provide care for the adult needing care, (b) whether the carer is willing, and is likely to continue to be willing, to do so, (c) the impact of the carer's needs for support ... (d) the outcomes that the carer wishes to achieve in day-to-day life, and (e) whether, and if so to what extent, the provision of support could contribute to the achievement of those outcomes. (Care Act, 2014, p. 10)

However, one significant obstacle to achieving the objectives of the Care Act is the issue of equality of access to resources for carers who come from seldom-heard communities. These communities can be 'BME groups, new migrants, asylum seekers, gypsies and traveller communities, people who live in rural/isolated areas, young carers or carers who look after and support people who have mental health or substance misuse issues', as well as the gay, lesbian and transgender community (Nottingham County Council [NCC], 2016a, p. 2). The Carers Trust (2016), for example, has drawn attention to, and summarised, the unmet needs of four seldom-heard carer groups, in particular.

- **Youth.** There are about three million children who take care of family members with special needs. The main problem that they face is balancing their caring role with their own study and other social needs.
- **Mental Health.** It is estimated that one in four carers are mental health carers. The stigmatisation of mental illness in society means that these carers find it difficult to obtain consistent support for their role.
- **Learning Disability.** Around 2 per cent of the population has a learning disability and is cared for mainly by family members 'across all age ranges'.
- **Substance Misuse.** There are around 380,000 'problem drug users' in the UK. However, those who care for them are not 'currently receiving their legal rights to recognition, assessment and services'.

In short, it appears that some seldom-heard carer groups are encountering various difficulties in accessing support. Therefore, it is imperative that we

investigate the circumstances of different seldom-heard carers, and identify their needs, so that appropriate services can be provided for them.

According to the 2011 census, there were 90,698 residents identified themselves as a 'carer' in Nottinghamshire, and 5,000 of them are being supported by Nottinghamshire County Council. Following its appointment of a new Commissioning Officer to encourage seldom-heard carers to 'access information and support from both the Council and local NHS' (NCC, 2016b), Nottinghamshire County Council commissioned the Department of Social Work and Health at Nottingham Trent University to undertake some research on seldom-heard carers so that it might 'learn more about carers who typically do not present for Carers' Assessments and do not access NCC services or commissioned services' (NCC, 2016a). The main objectives of the research were

- a. to investigate the obstacles to carers gaining access to services provided by Nottinghamshire County Council, the NHS, and other, partner organisations;
- b. to determine what types of services and resources carers require, if they are to fulfil their role and also maintain their own well-being.

The findings of this study will help to identify gaps in services, supporting commissioning decisions to develop new or different services to meet the needs of 'seldom-heard' carer groups in Nottinghamshire.

This report presents the main findings of the research on seldom-heard carers in Nottinghamshire and comprises five sections. Section two, below, introduces the research design and gives an overview of how the fieldwork was conducted. Section three describes the main characteristics of the respondents. Section four reports the results of the analysis of the data gathered from carers and stakeholders;<sup>1</sup> while the final section lists some recommendations for addressing the needs of seldom-heard carers.

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<sup>1</sup> Stakeholders were service providers and community leaders.

## 2. Research Design

The research team adopted a qualitative approach to the research, using a semi-structured questionnaire to gather data from 40 seldom-heard carers and 11 stakeholders. The adoption of a qualitative approach and the inclusion of both carers and stakeholders as interviewees fulfilled the requirements of the research bid and was based on the recommendations of previous research studies on this topic (Li 2010; Tonkiss and Staite 2012; Care for the Carers 2013).

The research team designed the research by working in partnership with Nottinghamshire County Council and by reflecting on the results of previous research on carers in the UK.

First, Nottinghamshire County Council's Research Brief stated, explicitly, that a 'qualitative methodology' should be adopted (NCC 2016a).

Second, using information from the Research Brief and through further discussion, the research team and members of staff at the County Council identified relevant carer groups – that is, groups that fell into the category of 'seldom-heard carers' – as well as relevant stakeholders – that is, providers of services to seldom-heard carers (such as charities) and community leaders (leading representatives of communities in which seldom-heard carers are found).

Third, previous studies suggest that the voluntary sector, community associations and local government specialist teams play an important role in identifying the hardest-to-reach service users. According to Tonkiss and Staite (2012, p. 3), 'the best way to improve access to learning disability services for BME communities is through providing more information and improving communication channels'. Furthermore, they point out that the local authority community team and third sector organisations 'had significant success in engaging with BME communities – for example, they understood that the best way to build up contacts and disseminate information is through word of mouth' (2012, p. 5). Similarly, Li (2010, p. 22) found that success in providing services depends on the involvement of BME groups, the use of 'word of mouth' and making 'good use of volunteers from BME communities'. Care for the Carers (2013) emphasised in its strategic plan (2013-16) that networks, groups and community organisations helped identify 'under-reached carers' and that their involvement could 'build capacity in these communities to support carers in practical ways that make a difference to their wellbeing and health'.

Therefore, given the importance of community groups and ethnic associations mentioned in previous studies, the research team decided to

contact relevant, similar organisations with a view to enlisting their support for the process of identifying and interviewing seldom-heard carers.

In addition to generating primary research data from carers, the research team solicited the views of both community leaders and service providers concerning barriers that prevent their members/service users from accessing public services. By addressing the first research objective from the perspective of both service users and service providers, the research team generated a more comprehensive and thus more valid understanding of the obstacles facing seldom-heard carers when they attempt to gain access to public services.

The fieldwork for the project was carried out between 25 July and 5 November 2016, following approval of the research ethics protocol and completion of a risk assessment. The respondents were recruited mainly through referrals from Nottinghamshire County Council, with the support of its partner organisations, as well as through researchers making contact via email and telephone. A small number of respondents referred themselves, after reading the promotional literature relating to the research.

### 3. Characteristics of Respondents and Cared-For Persons

The research findings, which are reported here, are derived from data obtained through interviewing 40 carers and 11 stakeholders from the following carer and stakeholder groups, as shown in Table 1.

*Table 1: Seldom-heard carers and stakeholders*

<b>Seldom-heard carer group</b>	<b>Number of carers</b>	<b>Number of stakeholders</b>
Black and Minority Ethnic (BME) groups	8	1 church leader, 1 worker from a BME community organisation, and 1 worker from a statutory agency
New migrants/asylum seekers	3	1 service provider [Community & voluntary sector (CVS)]
Substance misuse carers	5	1 service provider (CVS)
Young carers	5	1 service provider (CVS)
Mental health	5	1 service provider (CVS)
Hearing impairment	1	
Young carers	5	1 service provider (CVS)
Carers in rural/isolated areas	3	

Gypsies and traveller communities	3	1 service provider (CVS)
Armed forces veterans	3	1 service provider (CVS)
Lesbian, gay, bisexual and trans-sexual (LGBT)	2	1 community leader
People who have acquired brain/head injury	2	1 service provider (CVS)
Total	40	11

### 3.1 Main characteristics of carers

Of the 40 respondent carers, the main features are as follows.

- 30 were female and 10 were male.
- 27 were 'White', four were 'Black/Black British', four 'Asian/Asian British', two 'Chinese', two 'Gypsies' and one was 'mixed'.
- 29 were born in the UK and 11 were born in other countries, including two from India and the remainder from West Germany, the Caribbean, Jamaica, Ethiopia, Nigeria, China, Hong Kong, Pakistan and Mongolia.
- 22 were between 18 and 64 years of age, 13 were over 65 years and five were under 17 years of age.
- 12 respondents were categorised as a home-maker, another 12 were retired, six worked part-time, three worked full-time, five were students and two were self-employed.

### 3.2 Main characteristics of cared-for persons

The cared-for persons have the following features.

- Nearly one third of respondents had been taking care of their husband (nine) or wife (three), nine had been looking after their son or daughter, seven their mother, one their father, three their partner, two their brother, two their mother-in-law, and four had been taking care of persons related to them in other ways.

- 70 per cent of persons cared for (28) lived with their carer, 12 lived in their own accommodation, whilst one stayed in a rehabilitation centre.

A similar number of adult carers (73 per cent) in England also lived with someone for whom they cared (Health & Social Care Information Centre, 2015).

It should be noted that typically respondents were taking care of someone suffering from multiple health problems.<sup>2</sup> Only nine people being cared for had **one** health problem, 17 had between **two and three** health problems, and over one-third (14) had **four or more** health problems. The five most common health problems among the persons being cared for were mental health (20), long-standing illness (19), physical disability (14), poor/limited mobility (14) and hearing impairment (nine).

### **3.3 Characteristics of community leaders and service providers (stakeholders)**

The research team interviewed two community leaders who had close contact with carers and nine service providers whose organisations were providing relevant services for carers. The age range of the respondents was from 27 to 53 years. Seven of them had been in their current position for more than five years, three for more than one but less than five years and one for less than one year. Most respondents (eight) were women, two were men, and one did not answer the question about gender. Of the 11 respondents, nine were 'White', one was 'Black' and one was 'Chinese'. Three respondents were born outside of the UK; they came from Romania, Somalia and Hong Kong, respectively. All of them had been living in the UK for more than 10 years.

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<sup>2</sup> Health problems listed in the questionnaire were dementia, a physical disability, poor or limited mobility, sight impairment, hearing impairment, a mental health problem, a learning disability or difficulty, long-standing illness, terminal illness, alcohol or drug dependency, brain/head injury, a positive diagnosis of HIV/Aids and other problems.

## 4. Main Findings

### 4.1 Time period and hours of care

Concerning the length of time they had been providing care,

- 32.5 per cent respondents had been looking after someone for a period of **under 5 years**,
- 47.5 per cent respondents for a period between **5 and 14 years**,
- 20 per cent of respondents had been undertaking caring duties for more than **15 years**.

In 2014-15, about 28 percent of carers in England had performed their caring role for 15 years or more (Health & Social Care Information Centre, 2015).

As for their weekly caring hours,

- 37.5 per cent of respondents had typically undertaken more than **100 hours** of caring work per week,
- 5 per cent of respondents had undertaken between **50 and 99 hours** per week,
- 27.5 per cent of respondents had undertaken between **20 and 49 hours** per week,
- 30 per cent had undertaken **19 hours** per week or less.

A similar number of carers (38 per cent) in England were reported to take care of someone for 100 hours or more per week (Health & Social Care Information Centre, 2015).

### 4.2 Type of care

Of the 15 caring items<sup>3</sup> listed in the questionnaire,

- 47.5 per cent of respondents were carrying out **10 or more** items of care;
- 30 per cent respondents were carrying out between **six and nine** items of care;

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<sup>3</sup> Caring items listed in the questionnaire were personal care, managing medication, help with eating and drinking, help with getting dressed and undressed, help with preparing meals, help with doing laundry, help with getting the person in and out of bed, help with doing shopping, help with household cleaning, help with transport to places outside the home, companionship to prevent loneliness, emotional support, keeping safe, dealing with incontinence and other types of help.

- 22.5 per cent of respondents **five items** of care or less.

The nine most common items of care were providing emotional support (90 per cent), providing safety (82.5 per cent), providing companionship (70 per cent), doing laundry (70 per cent), undertaking cleaning (67.5 per cent), administering medication (65 per cent), preparing meals (62.5 per cent), doing shopping (62.5 per cent) and providing personal care (60 per cent). Six respondents helped the persons for whom they cared to manage financial issues such as paying bills, claiming benefits and other daily expenses.

### 4.3 Carers' perceptions of their responsibilities

Nearly all respondent carers believed that it was their duty to take care of their family members. One white respondent claimed that "[i]t's human nature to look after people" (W9). Some argued that, because marriage is a contract, one is obliged to take care of one's partner. In response to the question of who should bear the caring duty, Ruth replied: "Oh me, definitely. I took my vows. You know, that's what you sign up for. You look after me and I'll look after him" (C53). Similar views were expressed by Margaret: "We have been married for 43 years. I don't see it as a duty as I am helping my husband who is also my friend" (C47). Another respondent said that caring "responsibilities are normal ... The person who took on the contract – that would be the intimate family group" (C51).

Regarding who should take care of her adult son, Mary replied: "Well, it is with obviously me, nobody else has got the responsibility as I'm the parent and it's what you need to do" (C39). Alice even stressed that caring for her young child was unconditional love:

*I have never had an experience before with kids with special needs. I've never thought in my life I would but then he came and I still love him unconditionally ... I feel like I have been given this assignment to do, and I just have to carry it out well, so I feel good as a mum. (C12)*

Katie, a young carer, believed that caring is her way of re-paying the debt she owed to her parent for caring for her:

*No, I don't think that I should be receiving money for caring for my Mum as she is my Mum. She has given birth to me and now it is time for me to pay back to her. I know that without her, I won't be here on this Earth. (C33)*

It should be noted that the perception of caring among BME respondents has been shaped by culture. According to David, whose organisation provides services for black and minority ethnic users, Asian and African

carers tend to live with parents and take care of them (W1). Cecile, who looked after her mum, stated:

*I need to look after her because she is my mum. I feel that I got a duty to look after her. Well, I think this depend on a culture thing ... my Mum and Dad are from Jamaica; I think that it is just a good thing to look after your parents (C4).*

Being an Indian, Alan was taking care of a son who suffered from alcohol and mental health issues. He stressed that

*It's my duty ... from a purely parenting perspective and cultural perspective ... Because he's my son, he's the person we love and it's our job to do it, and I don't think I should be rewarded for it [money]. (C10)*

A few respondents claimed that the persons they cared for felt more comfortable being cared for by them. This positive feeling is a source of reward for the carer. Wendy said that, because her mother-in-law did not want to stay in a residential home, she and her husband took care of her. She stressed that her mother-in-law "didn't want anyone else to look after her. Even in the hospital she didn't want anyone else so I used to go in to care for her" (C13). Joyce was glad that her husband "only feels comfortable with me doing it so it is me [my responsibility] really" (C21).

It should be noted that all respondent young carers were glad to help their parents. As Lucy stated,

*it makes Mum happy when I care for her; and also, when she is unwell, I know what to do straightaway. There are no negative impacts on me as a result of looking after Mum. (C32)*

Although most respondents believed that it was their duty to take care of their relatives, many of them also expected support and advice to be offered by the Government. For example, Lisa wanted the supportive team to take more responsibility for the care of her disabled brother (C27).

#### **4.4 The term 'carer'**

According to some stakeholders, service users thought that it was their duty to take care of relatives and did not regard themselves as a 'carer'. A frontline worker emphasised: "I can't even say how many conversations I must have had where people argue the point that 'I am not a carer'" (W9). She explained:

*I suppose for most of the ones we meet they don't consciously take on the caring role, do they? I mean most of them become a carer through*

*things like a stroke or, and it's just their duty, or I suppose they feel it's their duty as a husband, wife, parent, whatever. (W9)*

The above observation was confirmed by Rachel, who was taking care of her husband:

*I don't classify it as caring at all. He's my husband. I got together with him and he had already got PTSD (post-traumatic stress disorder). I knew what I was getting into; I'd just accepted it. I knew nothing different. It's just part of our life. (C52)*

Betty, a frontline worker who supported new immigrants and asylum seekers even claimed that "carer" is a "European/Western concept" that does not exist in Asian and African cultures (W4). In her view, looking after family members is "just your responsibility". As she explained,

*you weren't supposed to be a carer; you're just supposed to be carrying out your duty because ... so basically, they would just see it as their responsibility to look after their children and after their relatives. So, they do tend to congregate. So, there is an understanding of [the] wider ... family unit or family kin, so brothers, sisters, aunties, uncles would support each other and would see that as part of their natural role. (W4)*

Workers who served mainly white carers also felt that sometimes the term was a barrier to them communicating effectively with service users. They emphasised that taking on the role of carer was a gradual process and that people being cared for might feel ashamed about being a burden to family members, if those who were looking after them were labelled a 'carer'. Thus, the term 'carer' can bring tensions to a caring relationship, as it is associated with a feeling of dependence.

From the experience of Nelson, who was a stakeholder, many family members have little choice but to take up a caring role:

*Some of our families, they take on that role because there's nobody else to take on that role ... they're trying to support them [their family members], and they end up taking on this caring role. (W5)*

Similar opinions were expressed by another service provider:

*Some don't think they are a carer until carer support services come in. I think sometimes it's a gradual process. With others, it happens overnight such as a stroke. And then that's it. You're a carer now; that's your role. (W8)*

The gradual process of becoming a carer was confirmed by the experience of Ann, who was taking care of her son: "When something happens you

just have to get on with it and do it. You don't really think about it because you just got to do it" (C28).

The above evidence suggests that 'carer' is a strange term for some minority ethnic groups and that it is also not accepted by some white service users. Therefore, as one respondent suggested, the phrase 'looking after someone' may be a more effective way of facilitating the relationship between service providers and service users than the term 'carer'.

## **4.5 The impact of caring duties**

### ***4.5.1 Physical and psychological impact***

Most respondents said that the caring duties they undertook drained them of energy so that they felt tired, exhausted and stressed. With regards to caring for her mother-in-law, Lily exclaimed: "It is very hard work because she calls for me all the time. I feel tired" (C2).

While taking care of someone who had particular needs, carers also had to cope with their own physical and mental health problems. Of the 40 respondents, 27.5 per cent had one health problem, 20 per cent had between two and three health problems and 7.5 per cent had more than four health problems. Rebecca, who was taking care of a husband who was suffering from dementia, was concerned about her own health: "I had a shoulder replaced, which is now still painful. I am waiting for a knee replacement in September. I don't work because of this problem" (C3).

As the respondents had to cope with too many caring tasks, some claimed that their mental health had deteriorated. In particular, those respondents who were taking care of someone suffering from dementia, drug and alcohol addictions and mental health problems had to cope with the unpredictable behaviour and unstable emotional state of their relatives, who easily lost their temper and made excessive demands on them. Some carers who were interviewed said that they had some degree of worry and anxiety and that they could not sleep properly.

Thomas' health had deteriorated through caring for his partner:

*Yes, I have [had] diabetes since I have been caring for my partner and it has got worse due to the stress. My blood pressure is a lot higher than it has been for many years. So, it certainly has an impact on my physical health. I feel very tired on a lot of times because it is relentless. I come to work and then go home to look after my partner. It is just relentless. (C43)*

As a result of the pressures of caring, Doris (C40), Lily (C2), Shannon (C37) and Ruth suffered sleeping problems. As Ruth explained,

*I don't sleep very well. Things go round my head a lot ... But in the last month he's being ... awkward and various other things. So, it goes around in my head and I can't sleep. It got to the point where I went to the chemist and got some sleeping tablets from the chemist. (C53)*

For Alice these pressures also caused emotional problems:

*Sometimes I just burst out and start crying. It's a way of getting it out, even when there is nobody around me to actually talk to. I just start crying; I might cry for hours. At the end of the day, when I cry, I have a headache, I don't eat and it is more or less like I am just punishing myself. So, I have that problem with my emotions and I let it take a better part of me, which is not fair, but I can't control myself. (C12)*

#### **4.5.2 Social impact**

The social and leisure time of most respondents was restricted by their caring duties; they had little time to meet relatives and friends. 'Loneliness and isolation' was the most common feeling among the respondents.

Because of her husband's limited mobility, Bethany found it difficult to meet friends and celebrate birthdays:

*It is difficult not being able to go out. He hasn't been able to get out properly since last September ... We can't all go out for the kids' birthdays – we can go without him and we enjoy going out ... We feel very isolated; it is very difficult for all of us. I can't just go out for a coffee with a friend ... We don't want to have to rely on our friends for everything. (C11)*

The demands of caring had also had a negative effect on the quality of the relationship between Joyce and her husband:

*Sometimes I feel that I don't get any time for myself, if you know what I mean. I am always cleaning, shopping or looking after my children. I don't feel like I spend enough time with my husband only, as I am always helping him and we are not spending time like what couples do. (C21)*

Some respondents have mixed feelings about their caring duties. Deborah, who was looking after a husband who was suffering from dementia, said: "I sometimes get very tired, very irritable, very lonely. But other times, he's the love of my life and I enjoy every minute of it. But, it just depends on how tired I am" (C26). A few respondents claimed that, as a result of their relatives' health problems, they had more time to look after them, talk to them and develop a closer relationship with them.

### **4.5.3 Employment impact**

Respondents' caring obligations had affected their job choices and work arrangements. Some respondents worked only part-time because it was the only way to balance the demands of work and their caring duties. In order to take care of her son, Mandy had decided to give up some of her teaching duties and take up out-of-class work on a temporary basis (C20).

However, other respondents had decided to give up their jobs altogether in order to fulfil their caring commitments. Abigail had not worked for more than eight years because, looking after her mother "24 hours a day", there was "no time to go for work" (C1).

Moreover, owing to the unstable physical and mental health conditions of the persons for whom they cared, some respondents had to ask, on a regular basis, either to leave work early at short notice or to go to work late in order to deal with sudden incidents involving the persons for whom they cared. For example, Alan's work patterns were affected by the demands of caring for his son:

*I have had to leave work early on several occasions. And then go back to work. I work the night shift, in the evenings and weekends. Yes, it does. It definitely affects my job choices. I have to work unsocial hours. (C10).*

### **4.5.4 Financial impact**

Caring duties not only imposed psychological pressures on carers but also increased their expenses. As Ruth explained, "[t]here is always the petrol money, the groceries that he doesn't see but just happen to be there. It is draining this; it's draining. It really is" (C53).

Respondents who had little savings but relied on social security benefits as their only source of income had to manage a very tight budget, particularly if they had children. This was the situation in which Joyce found herself:

*I do get concerns sometimes like buying winter clothes and [making sure] the children have proper bed linen; and sometimes it is difficult with the amount of money we got. We have to budget for these things as well as grocery shopping as it is very expensive, especially with four children, when you try to feed them. (C21)*

As a result of taking care of her husband and two children, Mandy had found it difficult to meet her mortgage and debt re-payments:

*I'm currently managing to make mortgage payments and debt repayments but I have had to negotiate reduced re-payments on both of those things. So, every three months, I have to go through*

*everything again to get another three months' payment. I'm not sure whether I'm able to get it again so it is very precarious. (C20).*

Finally, those respondents, as illustrated previously, who had to give up their jobs in order to meet their caring commitments, faced a reduced income. One carer said that her financial conditions "aren't as good as they might be" (C53), while another carer reported experiencing financial hardship (C20).

## **4.6 Informal and formal support**

The extent to which respondents had access to a support network varied since this was influenced by their cultural background, the length of time that they had been a resident in the UK, the number of children they had and the relationship among family members.

Respondents who were born in the UK could obtain support from their close relatives. For example, Lisa mentioned that her older brother helped to look after her mother and "caring for Mum is a joint effort from the both of us" (C27). One respondent who had problems with reading and writing would ask her mother-in-law to read letters to her (C21).

Respondents who were native speakers sought support from various types of health and social care organisation such as the Citizens Advice Bureau, the Carers Hub, Carers Federation, XXXX, GP surgeries, Child and Adolescent Mental Health Services (CAMHS), Ambulance Services, nurses, as well as support groups organised by local councils.

In particular, two main carer organisations had offered important information and valuable support for the respondents. Deborah described the support she had received from Nottinghamshire Carers Hub:

A lady called XXXX always gives us help. We have got a dementia support person, at the CVS office, and the person who runs the day centre, she's usually got her finger on the button, and she'll always ask. I saw her this morning and told her what happened and they'll help. So, it's people like that ... we've got a voluntary group made up of sufferers and carers called dementia carers support group, and they're fantastic. Today they're on an outing that's all been paid for by a local company. So, we go on trips; we have regular meetings. If you've got any worries, you can ring any of them (C26).

Similarly, Hannah used services for young carers:

Carers Federation provides me with [a] young carer advisor, who helps me a lot. For example, I can't explain to my Mum how I feel and I ask the young carer advisor a lot of things that I can't convey to my Mum

...[It] organises days out for young carers. During these times, we could interact with people who are in the same situation and we get help from one another through sharing our stories with each other. (C33)

By contrast, respondents from minority ethnic communities mainly used NHS services and also sought advice from their family members and ethnic and religious associations. Both married and unmarried adult children, as well as relatives in their extended family not living with them, supported respondents from minority ethnic groups and traveller communities by looking after their children, paying them regular visits, providing emotional support, giving health care advice, dealing with unforeseen incidents and helping them to complete relevant forms.

Victoria, who was an Indian and was looking after her husband, stressed that she would do "whatever my son tells me to do. I depend on my son a lot. I rely on my son a lot. He lives here too so he does a lot to help out" (C7). Lily would approach a Chinese organisation, if she had enquiries about welfare benefits. She also took her mother-in-law to join a programme organised by the Chinese association. As Lily described it, "she eats food and all the time she wants to eat food when she is here. She is happy" (C2).

BME immigrants who had been living in the UK for only a few years tend to obtain support from community and religious organisations such as their ethnic associations and churches because, with close relatives living in their home countries, the extent to which they could draw on a family network of support was relatively limited. For example, both Bethany and Wendy were immigrants and received support from church friends (C11; C13). According to Bethany, their friends visited them and helped her husband to travel to church:

*Our friends help to get him in and out to go to church. They come and talk to us, support us. They visit us. We eat together on special occasions. There is a person who comes to visit us at least once every day. (C11)*

The BME respondents' heavily reliance on support from close relatives and ethnic organisations is related not only to culture but also to the issue of language. Both service providers and community leaders emphasised that language was the biggest barrier to the respondents gaining to access public services. As Betty, a service provider, pointed out,

*they won't necessarily be aware at all that external support services are available to them, the language being a major stumbling block with everything being written in English. About one third of the people we've seen sometimes are illiterate in their own language. The vast*

*majority – 80 per cent of our clients usually do require an interpreter; so English would be none or little. So, you obviously just take on the role and do what you can, and struggle with your family members.*  
(W4)

In Betty's experience, "[i]nterpreters are not adequately available at all" and the doors of public services "don't seem to be very open and accessible to them" (W4).

It should be noted that the extent to which both white and BME respondents can draw on social support will be limited by the stigmatisation of certain health problems. Some carers tended not to tell their friends about the health conditions/needs of the people for whom they were caring, if those for whom they were caring had mental health problems, drug and alcohol addictions or had a different sexual orientation. For example, Alan did not tell his friends about the condition of his son because "mental health is a stigmatizing illness, especially in the Indian culture. You cannot tell people about this thing" (C10).

Being a white carer, Mandy shared her experience of caring for a husband who suffered from an alcohol problem:

*It's actually easier since he's gone back into re-habitation because I kept most of it concealed. That way people didn't know what was going on. I have a very close family but I didn't want to tell them because, when you're dealing with an addict, it is all about lying and hiding.*  
(C20)

## **4.7 The needs of particular carer groups<sup>4</sup>**

### **4.7.1 Ethnic minorities and new immigrants**

Among ethnic minority and new immigrant communities caring practices are shaped by culture and religion, while for some of them the services available are limited by their immigration status. As a service provider emphasised, new immigrants encounter financial, psychological and social support problems. In particular, "they have no support from the UK Government [no recourse to public funds] ... their choice is restricted" (W1).

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<sup>4</sup> It should be emphasised that the needs of the carer groups described in section 4.7 cannot be generalised to the total population of these groups. This is because the sample size for each group was relatively small, ranging from two to five respondents from each group. To acquire a comprehensive understanding of the needs of these carer groups readers also need to consult other relevant studies.

Some BME carers do not know what services are available to help them. As Bethany exclaimed, “[m]ost of this was due to lack of information and knowledge. It was very hard. Nobody tells you what you’re entitled to or how to complete the forms” (C11). Another carer agreed: “Nowhere ... I have to do it myself. I have nowhere to get help or tips” (C6).

The self-help culture of some ethnic groups might discourage members from seeking external support. According to one community leader,

*people tend to confine everything within their own family – spouse and grown up children were quite involved in caring ... there is a bit in the culture that we try not to bother with other people or do everything themselves or ... [use our] close family members or friends. (W3)*

Another stakeholder drew attention to the way in which family pressures on carers affected their use of support services:

*That lady kept saying she can’t disrespect her husband. So, when she became his carer, even when she wanted to access support, she would probably want him to access support to give her a break from her caring role but she can’t. (W8)*

In certain cultures, women are expected to be the main carer and to take care of family members, including the mother-in-law, while caring duties are not limited to immediate family members but to members of the extended family. For example, a frontline worker pointed out that “it is generally the women around the family who come around to do the caring. The personal care comes from the women in the gypsy community” (W6). Similar expectations about the role of women in relation to caring can be found in Asian and African cultures.

In summary, on the one hand culture can mobilise family members to use collective resources to provide a comfortable care environment for people in need. On the other hand, it can be a barrier to carers from minority ethnic groups and traveller communities gaining access to public services because some family members emphasise self-help and independence, and feel ashamed about seeking external support.

#### **4.7.2 Mental health and substance misuse carers**

The findings of this study reveal that poor mental health and substance misuse are still stigmatising issues in society. As a result, carers and their families limit the amount of support they call on from friends in order to keep their problems within a close family circle. For example, Rachel admitted that “[w]hen we first got together, telling family you’re with someone with mental health issues is difficult, and he didn’t want them to know. If anybody asked him, he left the army with his knee problems, not PTSD” (C52). Similarly, Shannon had not wanted her friends to know about

her son's mental health issues for some years: "I see my friends and for a long time, I didn't say to anyone what was going on at home" (C37).

One of the stakeholders also emphasised that there is a stigma in society attached to addiction to illegal drugs and alcohol: "People may think that the problem is caused by parents or family issues" (W5).

Moreover, some carers are unable to access services because their needs make them ineligible for support. A frontline worker pointed out that carers for persons suffering from substance misuse are unable to gain access to a carer's assessment: "Not one of our carers could get an assessment because they weren't eligible. So, to say that all these people could access a generic service but they were to be told that they weren't eligible ..." (W5).

#### **4.7.3 Young carers**

Young carers' relationships with friends might be affected by the health problems of family members. For example, the difficulty of explaining her younger brother's behavioural problems had deterred Megan from asking her friends to come round to her house (C31). Sometimes, young carers also do not know how to cope with unforeseen situations involving those for whom they are caring. As Hannah put it, "I feel stressed and nervous a lot of times, when Mum bursts out crying or feels drained" (C33).

#### **4.7.4 Gypsies and traveller communities**

According to the respondents, there is a strong self-help culture within traveller communities so that they will not actively seek support services. A service provider mentioned that traveller communities may not trust providers of public services:

*They take it [caring] on as a real family responsibility. They won't send their older people into a home as it is against their culture. They tend to keep very in-house, and it is within their own family. They are very close knitted. I have encouraged them but they are very scared of outside services. They have that fear: they think they are going to take somebody away from them, especially social workers. (W6)*

#### **4.7.5 Lesbian, gay, bisexual, and trans-sexual community (LGBT)**

Respondents from the LGBT community revealed that their social circle was relatively small. Thomas admitted that "[w]e never really socialise and we certainly don't have any gay friends. We have a few people around us like neighbours and we don't go out as we can't afford to" (C43). He explained further: "We are private people and we don't ask friends for help".

A community leader mentioned that it is hard for transgender carers to obtain appropriate services because their needs are unknown to service providers:

*The major caring roles that trans people are having are things like helping them get out of the house, advocacy, talking to services. It's very difficult for trans people to even do simple things like make phone calls. (W10)*

This leader added that caring for a marginalised person means that “the stigmatisation falls on the partner and carer themselves” (W10).

#### **4.7.6 Carers for people who have acquired a brain/head injury**

According to a service provider, this group of carers is isolated and sometimes has a strained relationship with the people for whom they provide care:

*The carers themselves are under immense pressure. There is instantly this dynamic shift when a person is injured, and communication becomes a big challenge. There are lots of difficulties with mental health problems and difficulties with personality changes ... The carer and the injured person become more isolated, also often from each other. This then leads to a family breakdown. Often a person with a brain injury will have very extreme behaviours and eventually their situation worsens, until they hit a crisis point. (W11)*

#### **4.7.7 Armed forces veterans**

Typically, respondents in this group were looking after someone who was suffering from mental health problems and who had limited mobility. According to one respondent, their spirit of self-reliance meant that some armed forces veterans are unwilling to seek help:

*But it's so hard for them to ask for help. They'll have never had to ask for help before. In service life, they are the people that help other people. They are conditioned, and they just find it so difficult to ask. (W12).*

In response to the question about the carer's assessment, Noah, who was looking after a wife suffering from various health problems, said:

*I see the information from Carers Federation and all that stuff. But I don't even bother reading it because the tone of it is so ... It doesn't attract me in. I guess I do know about the assessment but I haven't done anything about it. (C51)*

## 4.8 Experiences of the carer's assessment

Of the 39 valid responses, 29 respondents had heard about the carer's assessment and nearly 70 per cent (20) of them had undertaken it. Respondents who had completed a carer's assessment were mainly young carers or carers who suffered from mental health problems.

Some respondents had a basic understanding of the purpose of the carer's assessment. A young carer described the benefits that she received following a carer's assessment:

*I have taken the assessment three times (Year 5, 7 & 9). It is good and the young carer advisor is helpful and supportive. The assessment is a way of telling people what you do as a carer and how you feel as a carer ... They also, after the assessment, check how beneficial it's been after a few weeks; like, the last one I paid for my ice skating and a bus pass, which was helpful. So, I can go places more independently.*  
(C31)

Cecile also had a positive experience: "The experience was good and it was just as last year: I did one carer assessment and I get a respite, about £150" (C4). Similarly, another respondent was satisfied with the assessment process: "The process was straightforward; it was easy to apply, and I completed the interview over the telephone" (C39).

However, other respondents did not understand clearly the purpose of the carer's assessment. Because they thought that they were not eligible, they did not apply for an assessment.

One respondent, in particular, was very dissatisfied with the carer's assessment, as he could not obtain any support following the assessment. As he put it, "the carer's assessment was good but the promises were rubbish" (C46).

A service provider estimated that only half of their service users understood the nature of the carer's assessment. Another service provider noticed that there were several barriers to his service users undertaking a carer's assessment:

*It could take them quite a long time to complete, which is often off-putting for carers who have very little time to spare. They'll do something like that when they have time, but they'll often put it off – even more so for someone who thinks it won't be relevant to them. They'll ask what they're going to get out of it. If they know they're not going to get that much out of it, it's difficult to convince them.* (W9)

Similar views were expressed by another frontline worker:

*Some of our service users have suggested that the carer's assessment can give false promises to people about what they might be able to receive. When service users have to contribute to their own care packages through personalised budgets, it causes problems. Most people don't believe that their worth as an individual or as a carer can be properly financially valued. Overall, I think the assessment doesn't really fit with the needs of our service users. (W11)*

It should be noted that stakeholders in ethnic minorities and traveller communities believed that most of their service users did not know about the carer's assessment. One respondent said: "Somebody came to see me but I do not know who. She gave me £150 for the year to help me out, but it's not enough. He [the cared-for person] is getting worse every day. They just sent me a cheque and that was it" (C7).

As some carers had experienced different benefit assessments, they might have confused the carer's assessment with other social security assessments. For example, one respondent claimed: "Very negative. Didn't write anything truthfully. Had to go to panel and put the actual facts forward. It didn't go in our favour. We got a cheque from the Ombudsman but nothing else. No apology" (C6).

Other respondents commented on the length of time it took to complete the assessment. For example, Alice said that the carer's assessment "was a long process, but it was worth it eventually because at the end of the day they said, if I decide to work, to still be entitled to carer's allowance, you have to earn less than a £100 in a week. So, yeah, it's a bit complicated" (C12). Another respondent complained that, in relation to the carer's assessment, it "took too long to decide" the outcome (C11). Since applicants are notified of the result immediately following the completion of an application, it is likely that some of the respondents in this study had confused the carer's assessment with other types of benefit application.

In short, there was mixed feedback on the carer's assessment. Some respondents understood the benefits of the carer's assessment and undertook it; others had little understanding of the assessment and also confused it with other assessments. From the observations of stakeholders, it appears that some service users might have heard about it but that limited understanding of its content, fear of contacting statutory organisations, a strong self-help culture, stigmatisation associated with certain health problems and language barriers meant that their motivation for undertaking it was relatively low.

## 5. Recommendations for Practice

### 5.1 Promoting the carer's assessment

Some respondents had heard about the carer's assessment and also mentioned that they received some money as support. However, few of them knew about its contents, while other respondents had confused the carer's assessment with other types of assessment. Both stakeholders and carers gave several suggestions concerning the promotion of the carer's assessment.

Mainstream service providers believed that carer support groups were one of the most effective means of supporting carers, allowing them to share experiences and obtain advice from workers and members. They suggested that these could also be used as an opportunity to introduce carers to available services.

Both respondent carers and stakeholders mentioned the essential role that GP surgeries play in helping carers to understand their needs and in signposting to suitable support services. As one service provider pointed out, some carers will seek support from their GP because of the negative effect of caring on their mental health:

*It could be the treatment providers who will refer family members over, if they are working with substance use ... a lot of our carers are off work due to the stress of the situation. They're taking depression medication, as they start to become physically ill with the stress from caring responsibilities. They will be in touch with health care services so that they might be referred to us. (W5).*

One respondent proposed that more channels should be used to promote the carer's assessment. As she stated, "there should be more awareness about carer assessment on TV, hospital, health centre, in buses and churches and mosques" (C2). Other respondent carers suggested that various types of health and social care organisation should be asked to promote the carer's assessment, including GP surgeries, health centres and hospitals.

The role of community and religious organisations in supporting carers and connecting them to public services was widely recognised by respondents. A church leader explained the close relationship between his church and carers:

*One of our members got a stroke; he can no longer come to our meetings. So, what we did, we made regular visits to this person in the nursing home. We also paid visits to his spouse and family from*

*time to time, just to provide a bit of pastoral support ... [when] we discover the problem, the primary thing that we do is to pray for them as a faith community and to offer pastoral support and take things from there. Once they have let you visit them, you explore what are their needs, and we can signpost them. (W3)*

Some carers who are relatively isolated from mainstream society obtain services through outreach services and word of mouth. A service provider recalled the experience of contacting a relatively isolated carer group:

*Generally, it is through word of mouth. It might be a family member who would say that, "my daughter or my sister", and then you can pop around to see them. Their problems are basically caring for people who are not well. (W6)*

Leaders of the respondent organisations were willing to help promote the carer's assessment. As one community worker stated, "[i]f there is [an] information pack, I will give them to all my members. I will encourage them to go to the Council and have the carer's assessment done. Basically, it is word of mouth and passing it to people" (W2).

Therefore, Nottinghamshire County Council and its partner organisations can continue to work closely with social and religious organisations to enhance the accessibility of statutory public services to carers from ethnic minorities. However, it should be noted that, while BME community organisations have a vital role to play in providing access to BME and migrant communities, in many cases they are not in a position to assist with this without additional and dedicated resources.<sup>5</sup>

## **5.2 Rethinking use of the term 'carer'**

Our findings reveal that one common concern among stakeholders and carers is the concept of 'carer'. The term 'carer' was not welcomed by most respondents and had also become a barrier for frontline workers wanting to establish a positive relationship with service users. As one stakeholder emphasised,

*[m]ost people, overwhelmingly most people, don't want to be referred to as a carer, and they probably wouldn't recognise themselves as a carer at all. For most people, a carer is a professional who is paid to come in to look after someone they don't know. (W11)*

Another frontline worker shared the experience of his service users:

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<sup>5</sup> The conclusion was based on the view expressed by a respondent, as well as comments made by representatives of various organisations, during the fieldwork.

*In taking on the role of carer, thinking specifically of the wife, she wouldn't even think of herself as a carer normally. That's her role; she's the wife. This is what they tell me. In her role as the wife, they take on the caring duties. And I guess, if they are single and still living at home, the mother often takes on that role because she's their Mum; that's what they do. I don't think they realise how much they do for them, sometimes, to be fair. I don't think they even think about it; they don't think, 'Oh, am I a carer' or 'what is a carer'. (W12)*

One frontline worker "wish[es] we could just change the term carer". This is because service users are "often horrified when you happen to suggest to them that they are a carer" (W9). The illustrated evidence demonstrates that the term 'carer' does not reflect the actual experience of service users who are looking after their relatives. The term may even create an uncomfortable relationship between service users and frontline workers. Given that Nottinghamshire County Council has to follow central government guidelines and use the term 'carer' when advertising its services, it is proposed that the Council use additional, more sensitive words, when promoting its services to carers in the future.

### **5.3 Streamlined services for carers**

One issue arising from the research is the future service model for carers. There are several aspects to consider in relation to this issue.

- First, the effect of stigmatisation and family pressures is such that some carers require more personal support than others, while certain complex needs cannot be met effectively through carer support groups. For example, one frontline worker mentioned that an Indian service user was unwilling to attend a support group because "she can't speak about her caring role in a group" and "she didn't want her husband to know that she was having carer support" (W8). Therefore, individual counselling may be necessary for some carers.
- Second, counselling services, information and support for carers are currently provided by carer organisations as well as GP surgeries in certain areas, while the funding for supporting these services comes from different sources. According to one respondent (W9), one carer organisation operates a drop-in service in 12 different medical practices in the Broxtowe area. There are also three support groups for carers in Eastwood, Beeston and Stapleford. In addition, some medical practices have drop-in support and host special training and other events for carers.
- Third, it seems that different service boundaries between Nottingham City Council and Nottinghamshire County Council, as well as the

existence of different Clinical Commissioning Groups (CCG) that organise services for carers in a particular area, are causing variations in services provided to carers in different parts of Nottingham and Nottinghamshire. The present health and social care service boundaries between local councils and CCGs, as illustrated from the evidence in this study, has created unequal access to carer services across Nottinghamshire. Hence, some respondents believed that a coherent service, organised in different parts of Nottingham and Nottinghamshire based on GP clinics, might be one way of tackling this problem. The research team understand that the Sustainability and Transformation Plan proposed by the two Councils and the CCGs aims to tackle the issue of service access inequality. Therefore, it is recommended that effective actions be included in the Sustainability and Transformation Plan so that carer services are organised on the basis of GP clinics.

- Fourth, there is now a division of responsibility between two different carer organisations. One is responsible for identifying carers and referring them to another organisation that gives further support. As explained by one respondent, the main role of XXXXX is “about identification of carers rather than that ongoing work ... it’s more about finding carers and signposting on” (W9). The role of XXXXX is to follow up the referred cases. This means that some carers have to contact two organisations in order to obtain assistance. Therefore, in service development planning Nottinghamshire County Council should consider whether or not a streamlined service needs to be provided through a single organisation establishing a single point of contact for carers seeking assistance.

## **5.4 Training of frontline workers**

Given the complex needs of carers, as illustrated in this study, another issue concerns the training and qualifications of those working with carers. In particular, a significant number of carers experience stress and loneliness. According to one service provider, “I have had carers that I have supported who are caring for someone with mental health [issues]. However, they end up using mental health services themselves” (W8). Her views were echoed by another worker, who stated: “A lot of it is on their own health; a lot of it is emotional, isolation, through feeling overwhelmed, run down, depressed, things like that” (W9).

Similarly, another service provider pointed out the serious negative consequence of caring for others:

*Their mental well-being seriously deteriorates – like depression. They have no time for themselves. There is quite a lot of alcohol abuse because of that, not particularly illegal drugs. I have known a carer who has taken the prescription tablets of the person he is caring [for], as he is trying to cope with depression. (W6)*

One way of addressing the mental health needs of carers is to recruit frontline workers who have completed mental health support training or other relevant qualifications. In this way, frontline workers will be better equipped to manage complicated mental health issues affecting carers.

## **5.5 Communication between carers and care workers**

There is also a language issue for some carers from ethnic minorities who receive support. A community leader pointed out that “the spouse (carer and the person being cared) did not understand English, and hence it would not be a relaxing relationship with the carers” (W3). Given the potential for communication barriers to exist between informal carers from minority and ethnic communities and care workers, the Council and its partner organisations can consider recruiting more care workers who can speak English and other languages so that more culturally sensitive support can be offered to BME service users.

## **5.6 Access to support groups**

Some respondents mentioned the benefits that they received from attending carer groups. However, the scheduling of support groups may need to be revised in order to fit the employment patterns of carers. Thomas was disappointed that his full-time job meant that he was unable to attend a carers group held on a Tuesday morning. He suggested that “it will be beneficial for people like me to have it late afternoon or early evenings after work” (C43).

Another issue is the support available for carers who want to attend support groups. For example, one respondent had no choice but to take her husband, who suffers from dementia, to a support group because she could not find someone to look after him in her absence (C5).

## 5.7 The role of specialist organisations

The needs of some carers are relatively complicated such that they require special knowledge and also the involvement of various health and social care professionals. Looking after a person who misuses illegal substances is one example. Bernard, a carer, had described how his family obtained support from XXXX [an organisation that offers relevant services] to help him address his grand-daughter's illicit drug use:

*We got our granddaughter to see Henry [a frontline worker] for a few times. XXXX came to the house and we had a family meeting ... I told XXXX that I was on the verge of committing suicide ... Sometimes she doesn't accept the help, sometimes it's very, very hard to get through to her, as I said that's why, when XXXX got involved with us ... She was arrested after smashing the house up. XXXX came to court with me with; he was there to support me. But, basically, without XXXX, I definitely would not be here. I would be dead and gone because that is exactly how I felt, if I didn't have XXXX. (C17)*

Bernard also mentioned that he attended a support group organised by XXXX, where he met people in the same situation. He added that "I got support from XXXX for my mental health and I also ended up going to the doctor's and having some help with the doctor's" (C17).

Simon, another service user also appreciated the work of XXXX: "[It] provides one-to-one support at a certain time. It gives you an opportunity to discuss strategies with them" (C19). Another carer had to live with the abusive behaviour of her partner. She received a lot of support from XXXX, which she described as "a lifeline for me actually" (C20).

XXXX also provides telephone support, an outreach service, a 12-week structured programme, workshops for substance users and their families, peer support groups and also psychological interventions for carers.

In short, the evidence above demonstrates clearly the importance of specialist organisations, such as XXXX, in providing intensive support and treatment for carers who have complex needs and who are in distress. However, XXXX obtains financial support from statutory organisations to provide services only for drug users who are in treatment. As a result, substance users who are not in treatment are, according to a respondent, "potentially going to have no support ... they could only access generic carers services which are not suitable for these carers" (W5). In order to provide support for carers, XXXX has to raise money from various channels such as the Big Lottery Fund, social enterprise charity shops, Bassetlaw District Council, the Police and Crime Commissioner for Nottinghamshire, Boots and through fundraising events. The interview data suggest that existing funding support for specialist organisations such as XXXX is

inadequate and that, as a result, some carers are unable to access appropriate services to address their problems. This is an area that local councils and other funding bodies need to address as a matter of urgency.

## **5.8 Sustainable funding for CVSs**

The provision of services for carers has been constrained by inadequate financial support, a short-term funding policy and unreliable funding sources. As illustrated in the previous section, many carers experience distress, loneliness and depression. With limited resources, service providers are unable to offer intensive support for carers experiencing these health problems. According to one frontline worker,

*[t]he biggest need for carers at the moment, where there is probably still a gap, is around emotional support ... when resources are getting cut here, there and everywhere, we have less time to talk to carers. We haven't got the resources or remit in our services ... don't have the money, time or resources to do something like call a carer once a week for a chat for an hour. (W9)*

Moreover, without sufficient long-term grants, another organisation had to submit numerous grant bids, seeking financial support from a wide range of sources. Unfortunately, the success rate for grant applications in recent years is around one in 19. The amount of grant received is also relatively small (for example, £1,000). As a result, some organisations need to bid for different grants in order to maintain their services. One respondent had become frustrated as a result of the difficulties in obtaining grants:

*It's very difficult to navigate the world of funding these days. For instance, we work with 11 different funding bodies relating to the NHS, all of the different CCGs ... (W11)*

Given this funding environment, service providers have to spend a lot of time preparing grant submissions, with the result that they have less time to spend providing direct services. Hence, the respondent urged that the current practice of short-term funding needs to be revised:

*Sustainable funding would help services to be more effective and to plan better. It would help services to be more joined up, changing the effects of the political cycle and its knock-on effects on the NHS, on social services and on local services. To be effective we need stability. We need to be able to plan for the future. (W11).*

The reported problems for supporting specialist organisations that provide social and health services for people who misuse drugs and for their carers are related to differences in duties established between Nottinghamshire

County Council and CCGs as well as the strict requirements of EU procurement legislation. Nottinghamshire County Council is responsible for meeting the welfare needs of its residents, while CCGs are expected to meet the health needs of the population within their geographical area. As a result, a comprehensive service would need to be funded by different agencies. Furthermore, it may be difficult for a specialist organisation to continue to provide services to carers, if it fails to obtain a service contract through a process of competitive tendering.

Therefore, since CVS services are essential to the well-being of carers, the Sustainability and Transformation Plan may need to address the issue of how to fund specialist organisations jointly to deliver a comprehensive and consistent service for carers and their families. Moreover, since the current short-term approach to funding has impeded the development of social services agencies and the provision of stable support for carers, relevant funding agencies should re-examine the current approach to funding and consider the possibility of offering a longer contract for carer organisations.

## **5.9 Conclusion**

The findings of this study have illustrated that respondents have encountered tremendous challenges in fulfilling caring duties, including deterioration in their physical and mental health, limited time for social activities, financial hardship and employment disruption. In particular, respondents who were looking after someone with drug and alcoholic misuses, dementia and mental health problems experienced stigmatisation that had restricted their social support. For BME carers, language was the major barrier preventing them from accessing public services. For carers from traveller communities, a strong self-help culture and lack of trust in social services had discouraged them from seeking external support. In order to promote the well-being of the carer respondents, funding organisations may need to change their approach by providing more long-term financial support to carers' organisations in order to offer consistent services. In particular, specialist organisations need to be adequately financed to support carers with complicated needs. The term 'carers' should also be reframed to reflect the experiences of the respondents in taking on the role of carer and also to facilitate communication between them and health and social workers. Thus, adequate support for carers not only helps them to fulfil their duties and recognise their contributions but also promotes their social and mental well-being.

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