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Support Needs of Carers in North Lincolnshire

NHS North Lincolnshire

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Introduction

1.1 Background

The UK population, alongside that of many other advanced economies, is ageing. People are living longer with long-term health conditions and disabilities and the number of working-age adults with learning disabilities in the UK is set to rise over the next two decades (Carers UK, 2012). As a consequence growing numbers of people are in need of care and much of this care is provided by carers¹. There are an estimated six million carers in the UK, and this number is growing. Figures from the Census 2011 show that there are nearly half a million extra people in the country devoting more than 20 hours a week to looking after family and friends than there were a decade ago. At the current time, one in ten residents of England and Wales (5.8 million people) are devoting at least part of their week to caring for a disabled, sick, or elderly relative, an 11 per cent rise from the 5.2 million carers recorded in the 2001 census. The greatest increase in carers was among those providing over 20 hours a week of care, with the number rising from 1.66 million in 2001 to 2.1 million in 2011. Nearly 300,000 more people are dedicating 50 or more hours a week to caring for people, with the figure now standing at 1.36 million (*The Daily Telegraph*, 11 December 2012).

Data from the 2011 Census show that the number of carers in North Lincolnshire has also continued to grow, mirroring the national trends. In 2001, there were 15,952 carers in the sub-region, the comparable figure for 2011 being over two thousand higher at 18,161 (nearly 11 per cent of the population). In 2011 over 11,000 people in North Lincolnshire were providing between one and 19 hours per week care, 6.6 per cent of people who live in North Lincolnshire. A further 2,381 people were providing between 20 and 49 hours care. 4,684 people were providing 50 hours or more of care every week (see www.neighbourhood.statistics.gov.uk).

1.2 Policy Context

It has been estimated that if the care that unpaid carers provide nationally was replaced by paid help, their care would cost £119 billion per annum (Buckner and Yeandle, 2011). Carers therefore represent an important resource to the UK economy and there is widespread recognition (including across all political parties) that there is a need to support carers in the valuable activities that they undertake.

The publication of the first National Strategy for Carers in 1999 signalled central government's recognition that carers need greater support than had previously been available to them (HMG, 1999). A new range of policy developments and legislation directly affecting carers followed, as did a revised National Carers' Strategy in 2008 and a 'refreshed' National Carers' Strategy in 2010 (HMG, 2008; 2010). Two large central government funded programmes charged with exploring different methods of supporting carers were launched around the same time: the Caring with Confidence programme in 2008, which represented a £15.2 million investment in providing training and support to carers; and the National Carers' Strategy Demonstrator Sites programme in 2009 where 25 sites around England received central government funding to pilot three broad kinds of support for carers: breaks; health and well-being checks; and support through the NHS.

Many other locally based initiatives to support carers have also been introduced around the country, including in North Lincolnshire. A Carers' Support Centre has been operating in Brigg (located to the east of Scunthorpe) for many years, providing valuable support services to carers in Brigg and other parts of North Lincolnshire. NHS North Lincolnshire is currently

¹ A carer is a person of any age, adult or child, who provides unpaid support to a partner, child, relative, or friend who could not manage to live independently or whose health or well-being would deteriorate without this help. This could be due to frailty, disability or serious health condition, mental ill health or substance misuse (Carers Trust, 2012).

considering whether to establish another two 'hubs' in North Lincolnshire to provide additional support to carers.

1.3 Aims and objectives of the research

This report presents the findings of a scoping exercise to assess the support needs of carers in North Lincolnshire. NHS North Lincolnshire commissioned CIRCLE (Centre for International Research on Care, Labour and Equalities), at the University of Leeds, to carry out the research in order to inform and guide policy.

The key aims of this research were to:

- Assess the support needs of carers in North Lincolnshire (focussing predominantly on the views of carers).
- Provide information on good practice in relation to supporting carers in North Lincolnshire drawn from North Lincolnshire itself and nationwide.
- Provide policy recommendations to NHS North Lincolnshire relating to how they and their associated partners, such as North Lincolnshire Council, can respond effectively to the support needs of carers in the sub-region.

1.4 Research methods

To assess and examine the needs of carers in North Lincolnshire a four strand approach was taken which involved: focus/discussion groups with carers; individual interviews with carers; in-depth interviews with stakeholders; a consultative poster display.

Focus / Discussion groups

Ten discussion/focus groups with carers were held between September 2012 and January 2013. These comprised eight focus groups with carers held in different parts of North Lincolnshire, a discussion group with carers at the Annual General Meeting of the Carers' Support Centre at Brigg, and a discussion group with carers at a minority ethnic family fun day event. The objective was to ensure that the views of different kinds of carers, living in different towns and villages across the area, were captured. As table 1 shows, the focus/discussion groups enabled the research team to consult both male and female carers; carers living in different geographical areas, including those living in both urban and rural communities; carers of people with different medical conditions; carers of different ages, ethnic backgrounds, and employment circumstances.

Individual interviews with carers

In addition to the focus group discussions, eight interviews were carried out with individual carers. These were conducted face-to-face at the Carers' Support Centre AGM and the minority ethnic family fun day, and via telephone to one of the largest employers in North Lincolnshire.

In-depth interviews with stakeholders

We also carried out eleven in-depth telephone interviews with stakeholders who work with carers in the health, social care and voluntary and community sectors, providing services or other types of support to carers (for a list of interviewees, see appendix 1).

Consultative poster display

A further element in the research process was to gather the views of carers through a 'consultative' poster. The objective of the poster display was to reach as wide a range of carers as possible, and to capture the opinions of carers beyond those who were spoken to in focus groups and individual interviews. Posters were displayed in five venues across North Lincolnshire, listed in table 2.

The findings in this report therefore represent the *perceptions* of carers and stakeholders of the support needs and existing provision, which are supplemented by good practice recommendations drawn from other local and national research.

Table 1 Focus group participants

			Characteristics of carers							
Focus group no.	Location	Brief description (no. of attendees)	Young	Older	Rural	Urban	Employed	Minority ethnic	Male	Female
1	Scunthorpe	Carers of people with mental health issues (11)		✓	✓	✓	✓		✓	✓
2	Brigg	Ex-carers (8)		✓	✓	✓				✓
3	Scunthorpe	Carers of people with different health conditions (12)		✓	✓	✓				✓
4	Brigg	Carers of disabled children (10)			✓	✓			✓	✓
5	Scunthorpe	Carers' Advisory Group (5)		✓	✓	✓			✓	✓
6	Barton	Carers of people with different health conditions (17)		✓	✓	✓				✓
7	Scunthorpe	Carers of people using alcohol or drugs (5)	✓		✓	✓	✓	✓		✓
8	Scunthorpe	Carers of people with different health conditions (2)				✓	✓		✓	✓
9	Brigg	Carers' Support Centre AGM (circa 100)		✓	✓	✓			✓	✓
10	Scunthorpe	Minority ethnic family fun day (circa 50 people attended)				✓		✓		✓

Table 2: Poster venues

Venue	Location
Local Link office	Brigg
Local Link office	Scunthorpe
Crosby Community Association	Scunthorpe
Pakistani Islamic Centre	Scunthorpe
Sainsbury's supermarket	Scunthorpe

Data analysis

All data gathered through these different research stages were anonymised, recorded on appropriate software packages and analysed. The qualitative material was analysed in terms of *themes* and *issues*, with recurring items and issues of especial significance identified.

The remainder of this report is divided into eight sections, each of which explores the different kinds of carer support services currently available in North Lincolnshire, as well as both stakeholders' and carers' perceptions of the existing provision. Section two looks specifically at the need to identify carers; section three explores the information and advice available to and required by carers; section four looks at the provision of carers' breaks; the fifth section examines the kinds of education and training provision for carers; section six looks at employment support for carers; section seven examines carers' health services; section eight reviews the ways in which carers can get involved and engaged in service design and delivery; and the final section outlines the conclusions and policy recommendations.

2. Identification of carers

2.1 Introduction

Carers often possess intimate knowledge and experience of the needs of those they care for and, as outlined in the previous section, carers are essential to the health and social care system. Nevertheless, research (Graham 1985; Henderson, 2001; Stiell et al 2006; O'Conner, 2007; Yeandle et al, 2007a) has shown that carers:

'do not always feel recognised or valued by health and social care professionals; are sometimes reluctant to seek help; may feel isolated, unsupported and alone; and can sometimes be completely 'hidden' from those responsible for planning and delivering health and social care services' (Buse and Wigfield, 2011:50).

One of the key issues emerging from evaluations of programmes designed to support carers such as the Caring with Confidence and National Carers' Strategy Demonstrator Sites programmes (Yeandle and Wigfield, 2011a, 2011b) is, in fact, that carers are difficult to identify (and often do not identify themselves as carers).

As Buse and Wigfield (2011:50) point out, there are many explanations for the difficulties associated with identifying carers:

'some do not see themselves as a "carer" (or do not wish to accept this label), or may care for someone who is reluctant to make contact with service providers; others are unaware of available support and services and how to access them, or feel they would not be eligible for assistance; some feel their understanding or knowledge of the person they care for has been (or would be) disregarded or dismissed by professionals, or that they have been excluded from decisions about their caring role'.

There is evidence that some carers are more likely to remain unidentified or 'hidden' than others. These include, for example, carers in some ethnic minority or faith groups, young carers, and carers of people with mental health conditions, and drug and alcohol users (Perry et al, 2001; Harper and Levin, 2005; Yeandle *et al*, 2007b; Smyth *et al*, 2011).

2.2 Carer identification in North Lincolnshire

This section of the report looks at issues relating to carer identification in North Lincolnshire. Stakeholders and carers were asked what measures there were in place currently to identify carers, who carries out that identification, and where it takes place. Specifically, they were asked about activity in this direction in relation to: general practices; hospitals; schools; community organisations; employers; supermarkets.

Two key issues in relation to the identification of carers were raised in the consultations with carers and stakeholders. Firstly, it was pointed out that carers often do not recognise themselves as carers, and that it is only when this happens that they are likely to call upon support services for assistance, and only at this point that they themselves might begin to identify their own needs. Secondly, there were suggestions that those who do identify themselves as carers are not always recognised and identified by the health and social care system. This mirrors research that has been conducted elsewhere and nationally (see for example, Yeandle and Wigfield, 2011b).

Carers' self-identification

Many carers and stakeholders who were consulted for this report said that people who carry out caring on a regular basis often do not identify themselves as carers, thus confirming the

findings of other research. One carer, for example, said that she had looked after her parents for a number of years but did not see herself as a carer. Another carer similarly told us:

'I didn't see any need to tell anyone...it's just a duty.'

The view expressed above was, in fact, a commonly held sentiment and was replicated by a stakeholder working with carers and the people they were caring for:

'People don't always see themselves as a carer. They tend to be identified once they're into services.'

Some stakeholders said that carers of alcohol or substance users are particularly difficult to identify, partly due to the stigma associated with alcohol and substance misuse and partly due to the fact that those being cared for are not seen as 'deserving'.

Identification by the health and social care system

Both carers and stakeholders pointed to the existence of mechanisms in place to identify carers at various points of entry to the health and social care system in North Lincolnshire. A local NHS foundation trust, for example, was cited in the consultation process as providing services for people facing mental health issues and learning disabilities in North Lincolnshire, and being able to identify carers at the time of patient assessment, where one of the questions asked is aimed at identifying carers. It was reported that all carers are then entitled to a Carers' Need Assessment, and are told this.

The Carers' Support Centre at Brigg (CSCB) was also mentioned as having mechanisms in place to help to identify carers and subsequently offering them support services. The Centre employs part-time health liaison workers, for example, to work with general practitioners and other health care staff to raise awareness and to help identify carers. Staff at CSCB say that in recent years this has resulted in a large increase in referrals to the Centre. The CSCB has also established a carer champion in each general practice. Research elsewhere (Yeandle and Wigfield, 2011b; Wigfield and Wright, 2012) has shown that identifying carers through general practice is an effective strategy and indeed a programme to identify carers through general practice was highlighted in the social care White Paper in 2012 as an example of good practice (HMG, 2012).

The CSCB has used other techniques over the years to identify carers, such as engaging in discussions with people on wider issues and then raising caring as part of this discussion. For example, CSCB used to operate a welfare rights service, until funding for it ceased. Through the welfare rights service, staff made contact with households to discuss welfare benefits, and then took the opportunity to discuss other issues with them, such as issues relating to caring. As a key stakeholder said:

'We're trying to remove obstacles, and that's one way to go in and then ask if we can help them in any other way.'

The CSCB has attempted various other techniques and strategies to identify carers. Sometimes it organises stalls in public places with information and raffle-style participatory games, to raise awareness of carers and also to help to identify carers and help them to identify themselves. In late November 2012, for example, the CSCB held such a stall in Sainsbury's in Scunthorpe for almost the whole day. On other occasions the CSCB has tried to identify carers through more informal means, by making links with local shops and pubs.

It was widely recognised by stakeholders interviewed for this project that there are gaps in the health and social care system relating to the identification of carers. As one stakeholder said:

'Carers come to us once they are identified. Mostly they come through different departments and organisations, although a handful self-refer. There are lots of gaps, across the board. Even internally, there's a general consensus that we're missing out on picking up on carers. You can persuade GPs to start thinking differently, but one missing link brings the whole thing down.'

The CSCB has a policy of reaching out to carers and trying to identify them through pro-active measures. They have used newspaper articles to reach carers and, very recently, carried out targeted leaflet drops, and held three drop-in sessions. The response to these recent pro-active measures was, however, reported to be disappointing, with only four carers in total attending the drop-in sessions. Research elsewhere, for the evaluation of the National Carers' Strategy Demonstrator Sites Programme, for example, confirms that leaflets and posters are not always effective though some of the other mechanisms and techniques that CSCB have used, on the other hand, such as taking services to carers, and face-to-face contact, work well (Buse and Wigfield, 2011).

2.3 Summary

The perceptions of the carers and stakeholders who were consulted for this research can be summarised as follows:

- Many carers do not recognise themselves as carers, they see their caring activities as part of their duty to the cared for person, just part of on-going life.
- Many carers are not identified as being carers by the health and social care system. There is a consensus on this among stakeholders interviewed for this project.
- If carers are to be reached so that support services can be made available to them, they need to be identified by both themselves and by the health and social care system.
- The mechanisms for carer identification within the health and social care system itself needs bolstering. This means, in practice, ensuring effective mechanisms to identify carers through hospitals, clinics, and at general practices. It means making sure that general practitioners, general practice staff, nurses, and other health workers are made aware of the need to identify carers, understand their needs, and are aware sources of support that they can refer them to.
- The hesitation of some carers to come forward for support, and the fact that many carers do not even recognise themselves as carers, calls for the need to promote carer awareness and self-identification.

3. Information and advice

3.1 Introduction

This section looks at the carers and stakeholders perceptions of what assistance is available to carers in relation to information and advice. Carers and stakeholders were consulted on what information and advice is currently available, who provides it, and where it is provided, specifically in relation to: advocacy; signposting (for example, on carers' rights, entitlement to benefits, carers' assessments); financial advice; budgeting (paying household bills, benefits, debt); direct payments; and telephone helplines.

Carers told us through the consultation process that information and advice is important to them. The information needs to be both timely and relevant and presented in a way which is easy to understand. Carers explained that they need to know what to do in relation to financial support, support with caring, and innumerable issues emerging from day-to-day life as a carer. As one stakeholder said:

'The benefits are that having information empowers people to make choices and decisions about care.'

Another said:

'It's important because it makes them more confident and able to cope, like they're not up to their necks. It helps them understand diagnosis and prognosis, medication...it's empowering.'

3.2 Availability of information and advice

The consultation process highlighted that the two most important sources of information and advice to carers are seen as: on-line support through various websites; and the Carers' Support Centre at Brigg. Additional information and advice may well be available in the area, but was not mentioned by those who were interviewed.

On-line support

There are a number of websites that offer information and advice to carers in North Lincolnshire. North Lincolnshire Council, alongside other local authorities, has established a website, www.connecttosupport.org, which provides information on a range of issues for carers, including support options, money and legal affairs, transport, housing, health and well-being, and listings of current activities and events designed for carers. North Lincolnshire Council also runs telephone help service, albeit at limited times, and carers who contact the council are signposted to other sources of information and advice that are available in the sub-region. The Family Carers Team at North Lincolnshire's Adult Social Services also provides information to carers who are referred, or self-refer, to them.

A local NHS foundation trust also provides a website which offers information for carers, primarily on health conditions, medication, and on the health services provided in clinics in different parts of North Lincolnshire. Staff at the local NHS foundation trust also signpost carers to other appropriate services when they come into contact with carers.

A third source of on-line support is NHS North Lincolnshire which has a webpage dedicated to carers as part of its own website. This webpage contains: information on support available to carers; a link to a carers' newsletter; and a link to the NHS North Lincolnshire and North Lincolnshire Council's Joint Action Plan for Carers 2012-2014, which provides information on the overall NHS North Lincolnshire's budget allocation to carers, and outlines service delivery targets.

Another source of on-line support is through the Carers' Support Centre website, which outlines the help that they can offer in relation to information and advice, covering a range of topics such as carers' support groups, services offered at the Centre, as well as links to other useful websites.

This collection of on-line support provides highly useful information and advice for carers, although it must be remembered that many older carers do not necessarily have access to, or understanding of, such on-line support.

Carers' Support Centre

Six of the eleven stakeholders who were interviewed mentioned the Carers' Support Centre at Brigg when they were asked about sources of information and advice available to carers, demonstrating the importance of the Centre as a source of information and advice to carers.

The Carers' Support Centre has a telephone line open until 8pm most week days, and until 4pm on Saturday and Sunday, which carers can call for information and advice. The Centre takes a pro-active approach in the way that it disseminates information and advice, taking services to carers in recognition that carers cannot easily leave the person for whom they care. The Carers' Support Centre acknowledges the importance of the availability of information and advice to carers and as such designates resources to its provision, employing an information worker, and holding a database of carers to whom they can send important advice and information updates. They also provide a monthly information group for carers of people with dementia and, in addition to that, offer awareness training and the Caring with Confidence training programme.

The Carers' Support Centre also offers advocacy services, part of which involves obtaining information advice and accurate information.

Other support groups

Information and advice is also offered to carers by other support groups. Some support groups, such as Rethink (an organisation which supports people facing mental health challenges and their carers), and Empathy (an organisation which supports carers of people using alcohol and other substances), provide information and advice for specific groups of carers. Both Rethink and Empathy signpost carers to other sources of information and advice and Empathy also has a helpline which can be called 24 hours a day. Carers are also able to access information and advice from organisations which are not specific to carers, such as the Citizens Advice Bureau, Voluntary Action North Lincolnshire, and Crosby Community Association. A number of other organisations, whilst not necessarily offering specific information and advice to carers themselves, are involved in signposting carers to other sources of support, including the Alzheimer's Society, Mind and Voluntary Action North Lincolnshire.

3.3 Perceptions of information and advice available

Carers were asked, in focus groups and through individual interviews, about the availability, usefulness, and accessibility of the information and advice available to them, and how it could be improved.

Many carers argued that there is not much information available and that the information that is available is difficult to access. This viewpoint was very commonly held amongst the carers who were consulted but was particularly emphasised by carers of people facing mental health challenges, and by carers of people with physical disabilities. Some carers said that information is not readily available on where to find a support group that might then supply them with information and advice. As one carer said:

'It wasn't easy to find out information. I went for advice to the Crosby Community Association. They helped with filling in forms and things like that.'

Carers also said that, given that they often find it difficult to leave the person that they are caring for, the information needs to be easily accessible and that telephone helplines are particularly useful in this respect.

Even where information clearly does exist and is available, carers often do not know about it, or feel that they have not been told about it. Many carers said that it took a long time before they became aware of the Carers' Support Centre, for example. One carer said that she had been a carer for six years before finding out about a carers' support group, because no one had told her about it.

Another carer said:

'No one tells you about what is available.'

Some stakeholders also recognised the lack of awareness of information available as an issue. One said:

'There is a potential gap. I firmly believe that's a problem. There's no shortage of great work and information, but people don't always know how to access it or where to go.'

Carers and stakeholders also pointed out that information and advice needs to be provided at the appropriate time. In other words, carers need to receive timely information and advice, as soon as possible after assuming a caring role, or when the nature of their caring role changes. Many carers argued that information and advice should be made available to a carer by health social care workers at the very start of the process when a person becomes a cared for person. This means that health and social carer workers need to be involved in identifying carers when dealing with the person in need of care, providing the carer with relevant advice and information, and signposting them elsewhere for additional support.

Carers were particularly satisfied with the services provided by the Carers' Support Centre and all those who had used the service praised the Centre for the work it does in providing information and advice. As a carer said:

'You're always listened to – if they can't answer, then they find out for you.'

And another carer said:

'Information was available from the Carers' Support Centre. They would signpost. They were polite. There are no gaps. If you didn't understand, they'd tell you again.'

The telephone helpline is seen as particularly useful. One carer said, for example:

'The telephone is the point of contact for most carers – you're at it 24 hours a day, you're not out and about – is the telephone link which is extremely useful.'

The advocacy services offered by the Carers' Support Centre are particularly popular and the Centre reports that demand for these services is so high that they struggle to meet it within their existing service provision. Given the low awareness among carers of what

information and advice is available where, assisting advocacy provision by the Carers' Support Centre would be a worthwhile policy.

3.4 Summary

The perceptions of the carers and stakeholders who were consulted for this research can be summarised as follows:

- The provision of timely information and advice, that can be easily accessed, is crucial to carers.
- Information and advice needs to be presented to carers in different ways - on websites, through telephone help lines, face-to-face, through brochures, leaflets and posters - so as to reach the maximum numbers of carers.
- Information and advice needs to be taken to carers and presented pro-actively, as many carers have a low awareness of where and how to access information.
- The Carers' Support Centre should be supported in whatever way is possible by NHS North Lincolnshire and by North Lincolnshire Council, as it is providing an information and advice service which is greatly valued by carers.

4. Provision of breaks for carers

4.1 Introduction

This section looks at what assistance is currently available to carers in relation to the provision of breaks services. With the personalisation agenda in mind, we explored through the consultation process the extent to which tailored breaks and services which respond to the needs of individual carers are provided. We explored the kinds of support available for breaks, who provides that support, and where it is provided, as well as assessing the carers' and stakeholders' perceptions of the current support available and views on how improvements might be made in the future. A relatively wide definition of breaks services was taken, to include: respite, including specialised short-term respite; holiday breaks; sitting service/alternative care in the home; day care/lunch clubs; support with domestic tasks like cooking, cleaning, gardening, DIY; funding for equipment and/or activities

4.2 Availability of breaks

North Lincolnshire Council's Family Carers Team is able to award 'Carer's Payments', providing certain eligibility criteria are met. This can be used to purchase alternative care and provide money to pay for a break, or it can be used to pay for respite, or purchase domestic support. In addition to this, other support for breaks is available through the Carers' Support Centre at Brigg. The Centre receives grants to help carers access holidays, especially if they are on a low income. This does not mean, necessarily, that carers receive respite as sometimes carers wish to take the person that they care for on holiday with them, where obviously they continue their caring role. Furthermore where the person being cared for does not accompany the carer on the holiday, respite care costs are not covered.

The Carers' Support Centre also provide domestic support through its Home Support Service (previously known as the Home Care Service), at a charge to carers. The Home Support Service is provided in a sensitive and flexible way, so as to try to meet the needs of carers². The Service provides domestic and personal support to people who have a carer, which allows carers to take a break from caring. This includes personal care, domestic help, shopping, and any other appropriate activities that can help to take the pressure off the carer. The service can be provided for as little as one hour a week or for a full day and can be provided at different times: mornings; afternoons; evenings; or through a night sitting. The individual needs of carers are assessed on a one-to-one basis.

4.3 Perceptions of support available

The consultation process revealed that carers strongly appreciate breaks and respite care. Breaks benefit carers by providing them with some time to themselves, they help them to recuperate from their caring responsibilities, and as research elsewhere (Yeandle and Wigfield, 2011b) demonstrates, breaks help carers to continue their caring role, thereby avoiding expensive residential care admissions which can result from carer breakdown. One carer said, for example:

'To be given more time to yourself is crucial. You can't have your hair cut or have a bath or go to the dentist.'

Another carer mentioned that there is a big demand from carers for breaks and stated that:

'We're all in the queue for it [a break]!'

² The Carers' Support Centre at Brigg is registered with the Care Quality Commission to provide this work. The Care Quality Commission is the independent regulator of all health and social care services in England, whose role is to ensure that care provided meets national standards of quality and safety.

Similarly, a carer said that getting a break from caring would be a great benefit:

'It would be good to have somewhere we can leave them.'

Another carer said that what would be of most benefit would be someone to take her son to a venue which is supervised, and where there are some activities for him to engage in. This, she said, would give her and her husband, as carers, a really valuable break. Then they would be able to watch television when they want to, have a meal, have friends around. She said:

'Our lives were totally destroyed.'

Carers of alcohol and substance users, similarly to the other carers consulted, said that getting a break from the person they are looking after would be really helpful. It would help to reduce their stress and help them recover. However, they pointed out that providing breaks for this group of carers created a number of specific challenges. The person being cared for is often less likely to agree to respite care, even for a short period, as this would mean residing elsewhere. The alternative, of providing a break for the carer, is also problematic as it is difficult to find people willing to look after alcohol and substance users.

Despite the availability of both carer's payments and the breaks support provision through the Carers' Support Centre, most carers that were consulted for this research were unaware of the support available for breaks. Many carers said that there was nothing available to help them in relation to accessing breaks from caring, or in relation to accessing help with domestic support. Some carers said that there was nothing available to them in relation to breaks, trips, or domestic support. Carers said that if they wanted services like that then a support group would have to raise the own money for it.

Some older carers said that they did not have any help in this direction. One said:

'I never got support in that way.'

Some carers stressed the importance of help with domestic tasks and said that there was no help for this either.

Some stakeholders shared the view that there was little support for breaks. One stakeholder said that there used to be funding for a mental health support group that ran day trips and holidays, but this was no longer available. Another stakeholder, commenting on breaks for carers, said that there was:

'No respite care or alternative care that I know of.'

To facilitate respite breaks for some groups of carers, special requirements may have to be put in place for the people being cared for. For example, carers of people facing mental health challenges said in a focus group that what would help them, as carers, have a relaxed and rewarding respite break would be if the people being cared for could be taken on a supervised trip with other similar people. Importantly, the carers were concerned to make sure that the people being cared for were well looked after.

A stakeholder emphasised, also, that special requirements have may to be in place for certain groups. For example, the stakeholder thought that if respite care was to be provided for someone with certain mental health conditions while a carer took a break, the person providing the alternative care would always have to be the same person and would have to be someone that the cared for person knew. The extent to which this applies, and the

particular cases to which it applies, would have to be a consideration for health and social care professionals and obviously has resource implications.

A recurring theme throughout the consultations with carers was that they feared that the person being cared for might not get adequate care if someone else was looking after him or her. One carer said that she had left the person she cares for in the care of social services while she took a break which she organised and paid for herself. She said:

'they didn't look after him. I didn't get even a 'phone call from them.'

Some ethnic minority carers spoken to as part of this project felt that their particular cultural needs and those of the person being cared for would not necessarily be met if they used respite or alternative care. As a result the community attempted to help each other and provide their own alternative care arrangements. One carer said, for example:

'We rarely use respite care, because of cultural barriers and religious barriers. Things aren't done our way. If I knew of someone who needed some respite in the community, then I would help them out: the whole community looks after people. There is a gap here because if respite care was provided in an appropriate way, then people would use it.'

4.4 Summary

The perceptions of the carers and stakeholders who were consulted for this research can be summarised as follows:

- Despite the provision of Carer's Individual Payments and the grants for breaks available through the Carers' Support Centre, many carers believe that there is little or no support available to them in relation to funding respite, or alternative care so that they can take a break from the caring role. None of the carers that we consulted appeared to be aware of the Carer's Individual Payments, for example, or of any support available for breaks, trips, holidays.
- Carers would very much value more respite breaks. However, there are two issues that emerge related to this. One is that some carers are unable or unwilling to pay for such assistance. Another is that they fear for the safety of the person being cared for and they have fears about the quality of alternative or respite care provision.
- Some groups of carers have particular concerns relating to alternative or respite care, these include: ethnic minority carers who fear that the person being cared for will not be looked after in a way that meets the cultural norms within their own community; carers of people facing mental health challenges, where the cared for person may have specific requirements relating to continuity of care; and carers of alcohol and substance users, where the cared for person could be reluctant to agree to alternative care arrangements.

5. Education and training

5.1 Introduction

Education and training opportunities for carers are important for a number of reasons: they help ensure that carers can continue to have a life of their own; they can help assist carers to continue to work and/or learn alongside their caring role; they can help carers who have had to leave paid employment return to the labour market once their caring role has finished; and they are particularly important to young carers who need to establish their own career alongside their caring role. This section looks at the assistance that is available to carers in North Lincolnshire in relation to education and training, the perceptions of carers and stakeholders of the support available, and how improvements in education and training support for carers can be made. Carers and stakeholders were consulted on the education and training support available in a number of key areas: signposting to training and/or education; training in different skills (care-related tasks, domestic skills, DIY, gardening); the accessibility of the training in relation to times and venues; the specific training and educational support available for young carers who attend school, or wish to study at college or pursue university education.

5.2 Availability of education and training

Education and training support specifically for carers is provided in North Lincolnshire through four channels: training provision by the Carers' Support Centre; the Caring with Confidence programme; training provided by North Lincolnshire Council; support for young carers through schools.

Training provided by the Carers' Support Centre

The Carers' Support Centre recognises the importance of education and training, acknowledging that it helps carers realise their own aspirations, and helps them to retain a life of their own, both factors which are also recognised in the three National Carers' Strategies.

Where carers have had a carers' assessment, learning needs are identified and the Carers' Support Centre then tries to meet those needs. It provides courses for carers on areas such as First Aid and care for particular health conditions. It sometimes provides a financial contribution for books for carers who are enrolled on university courses. The Centre's base in Brigg is equipped with an IT room, from which computer courses are provided, and from where carers can access the Internet and be provided with support to do so. The Centre has some resources to provide training through funding targeted at Lifelong Learning activities. It also provides support by offering alternative care and transport for some carers wishing to attend education and training sessions.

The Caring with Confidence programme

The Carers' Support Centre also provides the nationally recognised course, Caring with Confidence, which aims to make a positive difference to the lives of carers and the people that they care for. The Caring with Confidence programme delivered at Brigg offers several modules, each of which deals with a particular aspect of caring: Finding Your Way; Caring and Coping; Caring and Me; Caring Day-to-Day; Caring and Resources; Caring and Life; Caring and Communicating. Importantly, the Caring with Confidence programme is delivered flexibly: carers can choose to come to some, or all, of the sessions, a sitting service (to look after the cared for person) can be provided, and transport costs can be covered.

Carers who were consulted for this research and who had attended the Caring with Confidence course appreciated the contents of the programme and the way it was delivered. One such carer said:

'I went to Caring with Confidence. It's essential, in my opinion.'

The national evaluation of the Caring with Confidence programme also showed that the programme was very popular amongst carers and had a positive impact on both their health and well-being and their ability to have a life of their own (Yeandle and Wigfield, 2011a).

Training provided by North Lincolnshire Council

Representatives of the Carers' Support Centre explained that training provided by North Lincolnshire Council for their own staff is also open to carers, although evidence from the consultation suggests that carers do not tend to make use of this provision, primarily because alternative care for the person being cared for is not provided, making it very difficult for most carers to attend. Interviews with representatives of North Lincolnshire Council confirm that this provision is available, although one stakeholder said that there were relatively few carers taking up the training, and suggested that not all carers felt comfortable attending training sessions with professional, salaried staff. Another factor which makes it potentially difficult for carers to attend this training, which would also apply to any other form of education or training provided, is that the locations where the training is delivered are not always easy to get to.

Supporting young carers at school

A stakeholder described how young carers at school receive support, noting that there are arrangements for students to leave school early, and that there are other ways in which young carers are provided with flexibility. Another stakeholder explained that simple measures can be implemented by schools to assist young carers, such as allowing them to use their mobile phones during the school day to check that the person they care for is all right, or allowing them to keep their mobile phones on in class in case the person they care for needs to contact them. The crucial element in being able to provide support of this kind, of course, is being able to identify the carer in the first place which, as explained in Section 3, is often a challenging process, particularly in relation to younger carers.

Another stakeholder explained that some young carers need assistance purchasing their own school uniform and other basic equipment for school, or benefit even from being accompanied to school at least initially so that they know where it is and the route to it.

A different stakeholder said that support is available within each school, once a young carer is identified. Young carers obviously have difficulties in juggling their caring and learning activities, although these are not always recognised and accommodated by the education system. This stakeholder indicated that some young carers can be late for school due to their care responsibilities and this may not be accounted for in the school records.

5.3 Perceptions of education and training

As with other areas of potential support for carers, there is a lack of awareness among many carers on what is available in relation to education and training. One carer said:

'I didn't need any support like this, but also I didn't know of anything that was available for me.'

Another, ethnic minority, carer discussing her family's knowledge of the availability of education and training for carers, said:

'We didn't know, and my auntie [main carer] didn't access anything.'

Similarly, in the focus groups, most carers were not aware of what support is available in relation to training, or where information on what is available might be found. Nevertheless,

some carers who were consulted did appear aware of training provision, and at least two had actually taken up support to train for new skills. In terms of where support should be provided, most carers expressing a view were primarily concerned that the training be made available in easily accessible venues.

Some carers, especially those associated with the Carers' Support Centre at Brigg, were aware of the Lifelong Learning opportunities, and of Caring with Confidence, both run at the Centre, and there was considerable support for both training opportunities. The support provided through the Lifelong Learning activities was strongly appreciated at a focus group, for example. One carer said that they were:

'An absolute gift. A local carer support worker arranged for us to go to a jewellery class. Another had a massage, another driving lessons, another was doing art.'

And a stakeholder, who is also a carer, said:

'Caring with Confidence is very good. I strongly recommend it.'

As when asked about breaks, many carers who were interviewed stated that they would worry about the welfare of the person they care for if they themselves were attending an education or training session, even if they have replacement care arranged.

Carers who were consulted for this research project said that they thought that they would benefit from training to assist them in their caring role, and carers who have had this kind of training in the past expressed strong support for it. One carer outlined just how valuable a course that used to exist – the Family Education Training Programme – had been to her. This course was a training course for new carers, providing information on different topics, including medication, understanding the medical condition, and other issues. She said:

'It was really important to us. It empowers you, and gives confidence. It lasted 6 weeks, maybe more. It introduces you to other carers and you form friendships, and you form a support group. That's one of the best things about it.'

Many stakeholders argued that a major gap in support provision available to carers relates to training on how to look after the person being cared for, and training on how to understand the health conditions facing some people being cared for. One stakeholder, for example, argued that there is little training available for carers relating to personal care of the person being cared for.

One stakeholder argued that there is specifically a lack of training to help carers of people facing mental health challenges to understand those conditions, and that an understanding is important to help the carer carry out their caring role effectively. The stakeholder gave the example of a carer looking after her son, who was experiencing psychosis, and hearing voices. The stakeholder said:

'No-one working with the son explained anything to her, or helped her understand his condition. She [the carer] was saying to the son that she could hear the voices too, to reassure him, and didn't know this wasn't the right thing to do until she came here to the support group. She couldn't believe no-one had told her that.'

This stakeholder went on to say:

'There's a big missing link in improving caring. The Caring with Confidence training doesn't always give practical skills.'

It was widely recognised by stakeholders that there are big gaps in the training provision that is available to carers. One stakeholder said:

'There are huge gaps. It's hard to understand what carers' needs are and what they need training in.'

Among the carers who were consulted for this research, beyond training in personal care and training to understand medical conditions, there was little demand expressed for education and training in any other subject or field, although this is hardly surprising given the lack of time that most carers have for themselves.

One stakeholder identified that there was a gap in relation to young carers, who she believed lacked support. The stakeholder said:

'There's a great lack for young carers, and this needs to be addressed, whether this is in relation to vocational or academic training or just a hobby...There's no support in schools. One teacher once said to me that there is a real pressing need around young carers.'

Another stakeholder said:

'I don't know of anything available to support people in school, college or university.'

Schools and colleges contacted for this research project were unable to identify how many of their students were also carers or, indeed, exactly which of them were also carers.

Throughout the consultations with carers that took place for this project, a predominant theme was the need for flexibility, whether it was in relation to appointments with general practitioners, breaks, or training provision. As one stakeholder said in an interview:

'Organisations need to be flexible when they deal with carers, and understand the latter's need for flexibility.'

And another stakeholder reinforced this view, saying:

'I don't think there is any flexibly delivered training.'

Another one carer again stressed this need for flexibility, saying:

'If there's something like that you can go to it needs to be flexible, because you can't always keep going to something every week – you might have to dip in and out of things.'

5.4 Summary

The perceptions of the carers and stakeholders who were consulted for this research can be summarised as follows:

- The provision of support for carers in relation to education and training is important because it can help carers to pursue their own aspirations beyond caring. Moreover, it would help to achieve one of the key objectives set out for carers in *Is knacarered a Medical Condition?* which stated that, by 2011, carers in North Lincolnshire would 'Be able to have a life of their own alongside their caring role'.
- Most carers are unaware of what support is available in relation to education and training.
- It would help carers if training was available in personal care and in understanding specific medical conditions, particularly in relation to mental health issues.
- Due primarily to time constraints there is little demand among carers for education and training in any other subject or field.
- As with all other areas of carer support, there is a need for flexibility in education or training that is provided for carers.
- As with many other areas of potential support available to carers, there is also a significant lack of awareness among many carers of the support that is available in relation to education and training.
- Simple measures to support young carers can be very effective but the extent to which schools are adopting these measures it is not entirely clear.

6. Employment

6.1 Introduction

Many carers attempt to combine paid work and caring, in fact there are an estimated three million people in the UK combining caring with paid employment. Indeed one in seven employees is estimated to be juggling paid work and care. However, evidence shows that the more hours a week that people engage in caring, the less likely they are to remain in paid employment. 75% of those who care for less than 19 hours per week are in paid work, but this figure falls to half for those caring for more than 20 hours per week (ONS, 2001). Research by IPSOS MORI in 2009 shows that many carers, one in six, give up or reduce work to care and the public expenditure costs of carers leaving paid work is £1.3bn per annum based on costs of carer's allowance and lost tax revenues (PSSRU, 2010). A caring role can therefore severely impinge on a person's ability to engage in paid employment. Numerous carers consulted during this research stated that they had had to reduce their working hours because of caring duties, or had given up their jobs altogether. This section looks at the perceptions of carers and stakeholders on the assistance available to carers in North Lincolnshire in relation to employment, and what additional support is needed. It explores the views of both carers and stakeholders in relation to support to: remain in employment; return to or enter employment, such as job application and interview skills; set up in business.

6.2 Availability of employment support

According to both the carers and stakeholders who were consulted for this research, there is not any specific support provided to carers in North Lincolnshire to help them gain paid employment, or to support those already in paid employment, apart from support that may be provided to carers by individual employers. Education and training can assist carers to enter or re-enter the paid labour market but, as seen in the previous section, there is little of this available specifically for carers. Given that many carers are forced to leave the paid labour market when becoming carers this is an area which requires some attention. The work of Carers UK shows that supporting a carer to remain in employment is an effective strategy, as once they have dropped out of the paid labour market they require much more intensive support to re-enter.

6.3 Perceptions of employment support

The 2006 Work and Families Act extended the right to request flexible working arrangements to many carers providing regular and substantial care (after six months in employment), but as the carers who were consulted for this research demonstrated, the legislation alone is not sufficient to make a difference. What is really important is an employer who is flexible, and can understand the needs of the employed carer. Indeed those carers in paid employment consulted for this project said that a sympathetic and flexible employer was a crucial factor in allowing them to continue working at their current level. A carer outlined how supportive her employer had been. She said:

'I couldn't have asked for better from my employer. There is someone to talk to if you need it, they are there for me, it is amazing. The employer supports me by being flexible.'

Some carers described how they relied on other members of the family to take on caring duties while they go to work. One carer said:

'Sometimes I am frantically ringing round trying to get someone who can pop in to see him. If I didn't have the support of family I wouldn't be able to keep up my job.'

Not all carers have sympathetic or flexible employers, however, or indeed supportive nearby families. As one carer said:

‘where I work, you can’t just say “oh I’ve got to nip off now to look after someone”’.

And another carer said:

‘Not everybody has somebody. For instance, I haven’t got any family I can call on to help me out.’

Another carer said that they had taken voluntary redundancy because of the pressures of dealing with the person that they care for.

When asked what kinds of support would be most effective in helping them remain in or return to paid employment many carers who were consulted said that the highest priority would be to have a sitter, someone who could call in occasionally to check that the person being cared for was all right so that the carer could go out to work and have ‘peace of mind’. Other carers said that a buddying service would be helpful whereby a friendly and supportive person (either a volunteer or social care worker or some combination of both), could act as a support worker, guide, or mentor for the cared for person for short periods of time, whilst the carer went to work.

One carer described how a similar buddying system had operated in practice while her husband was in hospital. Humbercare, an enabling organisation dedicated to providing quality and innovative services to adults and young people which works in North Lincolnshire and elsewhere in the nearby region, provided a buddying system. She said:

‘They did a bit of gardening, take them for coffee, go to the gym, had a general chat for a while. This happened once a week for a couple of hours. It was fantastic.’

Evidence from the evaluation of the National Carers’ Strategy Demonstrator sites programme (Yeandle and Wigfield, 2011b) also indicated that sitting services or befriending schemes provided by volunteers were both popular and successful.

There were various discussions in the focus groups about the opportunities that assistive technologies such as telecare and telehealth offer in enabling carers to undertake paid employment. Evidence from research elsewhere indicates that both telecare and telehealth can, in some circumstances, be a very effective tool in enabling carers to leave the person that they care for large periods of time (Yeandle and Buckner, 2007c; IRISS; Breen, 2011).

6.4 Summary

The perceptions of the carers and stakeholders who were consulted for this research can be summarised as follows:

- A sympathetic and flexible employer is a crucially beneficial factor in allowing carers to continue in paid employment. Other carers benefit from family support. Some carers have neither of these support mechanisms.
- Assisting carers to remain in employment is an effective strategy, once carers have left the paid labour market it is much more difficult to help them to return.

- There is very little specific tailored support available to carers in relation to trying to find paid employment or to support those carers who also work.
- Some mechanisms which could assist carers enter or return to paid employment are a sitting service, a buddying or befriending system, and more widespread use of telecare and/or telehealth in the homes of the person being cared for.

7. Carers' health

7.1 Introduction

Evidence from the evaluation of the National Carers' Strategy Demonstrator sites programme showed that various innovative strategies and services can help support carers to maintain their health and well-being. This section looks at what assistance is available to carers in relation to looking after their own health, as opposed to the health of the person that they care for. It examines both carers' and stakeholders' perceptions of the support that is available to them, who provides that support, where it is provided, and any improvements that could be made in this direction. A number of specific interventions were explored through the consultation process including: health checks (physical checks, mental well-being checks); peer and/or emotional support; flexibility of appointment times; the location of the health checks.

Carers need to remain in good health to be able to continue their caring role and to avoid carer breakdown. However, many stakeholders indicated that carers sometimes neglect their own health because they are busy prioritising the health of the person that they care for. As one stakeholder said in an interview:

'Often carers neglect their own health, and risk deterioration. It's about making sure they look after their own health.'

7.2 Availability of specific health support for carers

The Carers' Support Centre services

According to both the carers and stakeholders that were consulted, the Carers' Support Centre at Brigg offers the main source of specific support to help maintain carers' health and well-being and the Centre offers a variety of support in this area which includes: health liaison workers; advocacy; counselling services; the provision of support groups.

Health Liaison workers

The Carers' Support Centre at Brigg currently employs Health Liaison workers who aim to promote awareness of carers amongst health care professionals within the health care system. As part of this, the Health Liaison Workers provide staff with information about what support is available for carers so that health care workers can gain a greater understanding of the particular challenges that carers face and the health implications of these.

Advocacy

The Carers' Support Centre also provides advocacy for individual carers accessing the health care system, though its time and staff resources for this are limited.

Counselling

The Carers' Support Centre provides counselling to carers through volunteer counsellors who are in the process of being trained. This service is available free to carers and to recent former carers. Counselling offers the chance to explore thoughts and feelings in a relaxed and confidential way. This is especially useful to help relieve the sense that carers are alone with their problems, and it can help with feelings of guilt, anger, stress, bereavement or depression/anxiety.

Support Groups

Some support groups assist carers to maintain their health. The Carers Support Centre coordinates 14 such groups, which meet regularly. These are located across North Lincolnshire, in an effort to reach as many carers as possible, and some are aimed at specific groups, such as young carers, or at specific interests, such as badminton, family

history. To enable and facilitate attendance of carers at the support groups which it co-ordinates, the Centre provides free care for those being cared for. Transport is also provided, at a discounted rate. Wherever in North Lincolnshire the carer is coming from the charge is £2 return. They are able to provide this transport at such a favourable rate for carers because they use volunteer drivers. Representatives of the Centre state, however, that it is sometimes difficult to recruit volunteer drivers.

There are also other support groups for carers in existence in North Lincolnshire which are independent of the Carers' Support Centre but which also meet regularly, such as Empathy which, as already discussed, supports carers of people who have drug and alcohol problems, and Rethink, which supports carers of people facing mental health challenges. Some of these support groups have specific activities aimed at helping carers with their health. Rethink, for example, provide a carers' Wellness Recovery Action Plan (WRAP), which provides peer support, as well as involving people monitoring themselves in line with an agreed plan of action.

Carers' Needs Assessments

For those carers who have undertaken a Carers' Needs Assessment, a need might have been identified during that process for a carer to undertake an activity which might be beneficial to their health through, say, having a break (see section 4) or reducing stress by attending a gym. In these cases, funding from the local authority may be available for alternative care provision so that the carer can engage in the activity.

7.3 Perceptions of health support specifically for carers

Most carers were unaware of any services directed at helping them maintain their own health. The discussions in focus groups and in individual interviews suggest that no specific support services are provided especially for carers. Most carers said that there is nothing available beyond that which is available for everyone in relation to health care and well-being.

Many carers said that they were never asked about their own health by health and social care practitioners, though all of them would welcome some assistance and support in this area. As one carer said:

'You are never asked about your health, about how you are getting on.'

This viewpoint was expressed many times by carers during the consultation carried out for this report.

Carers also said that they value support groups strongly. A consistent theme, in relation to the support groups organised by the Carers' Support Centre and those independent of it, is that carers strongly appreciate the benefits, including the health benefits, of being part of a support group. Support groups help considerably in relation to providing emotional support for carers. In addition, attending support groups provides carers with a small break from caring and, at the same time, peer support, ability for social interaction, and a channel for practical advice. All this can benefit the psychological, and physical, health of the carer. Similar evidence from the evaluation of the National Carers' Demonstrator Sites programme emerged which indicated that peer support is a simple and cost effective way of supporting carers.

One carer described how, in the past, she could not wait to get to the first Thursday in every month for the carers' group meeting, where she would get peer support by talking to others in similar positions. And another carer said:

'You need someone to talk to sometimes, you have that with the support groups.'

The support provided by the Carers' Support Centre to assist carers to get to these meetings - through help with alternative care provision and cheap transport - is strongly appreciated by the carers themselves.

Carers stated in the consultation process that they would welcome attention being paid to their own health, as well as the health of the person that they care for, by health and social care practitioners. Regular health checks would be welcomed by many carers. As one carer said:

'Health checks would be an opportunity to raise issues or concerns, which would be useful.'

This supports evidence found in the National Carers' Strategy Demonstrator Sites programme which indicated that 95 per cent of the carers who had had a Health Check through the programme thought that this was a good way to support carers (Yeandle and Wigfield, 2011b).

Carers, in some rural areas of North Lincolnshire, said that there are no local general practices, where such health checks might normally be carried out, and also explained that public transport is poor. Some carers thought, therefore, that providing health checks through a mobile facility would be useful to carers, especially those who live in rural areas. As one said:

'it would be useful if it there was a mobile well-women clinic, like a mobile library, especially given transport problems in rural areas.'

Another said:

'A mobile unit would be perfect.'

Again this confirms what was discovered through the evaluation of the National Carers' Strategy Demonstrator Sites programme, that taking services, such as health checks, to carers is an effective approach. Indeed, some of the Demonstrator Sites offered health checks in carers' homes, in local community centres, and in sports centres and these were very popular. An equally popular service was the use of voluntary sector staff (with appropriate training and support), rather than clinicians, to carry out health checks (Yeandle and Wigfield, 2011b).

Many carers said, in the consultation process, that their caring role puts them under severe pressure. Many are caring 24 hours a day, seven days a week, with very little time to themselves, even for just normal day-to-day activities like getting washed. This, in itself, puts an enormous strain on carers, often leading to emotional stress, which they need assistance to deal with. This emotional stress was felt by many different types of carers, and was spoken about frequently.

Counselling can provide one way of dealing with stress, worry and anxiety. Counselling has helped many of the carers that were consulted and quite a number said that they had benefitted from it. One carer new to a caring role said, for example:

'The GP has suggested counselling. I did see a counsellor some time ago, for something completely different. From that, I learned coping mechanisms. I

probably wouldn't have coped at all without this [because of new caring role], but I learned the coping mechanisms.'

Carers also mentioned that they need flexibility in relation to appointments with general practitioners and other health and social care professionals. As one carer said:

'Being able to see a doctor at flexible times was very important.'

The availability of flexible appointment times for carers at general practices was again a strategy that was experimented with in some of the Demonstrator Sites and was something which worked very well. Another strategy that was equally positively viewed by carers in some of the Demonstrator Sites was the provision of sitters so that the carer could attend appointments at their general practice.

7.4 Summary

The perceptions of the carers and stakeholders who were consulted for this research can be summarised as follows:

- Carers may neglect their own health because of the challenges of caring for someone else's health and well-being.
- Many carers are under considerable emotional stress which presents a challenge to their health and emotional well-being, and need to be provided with opportunities to help them deal with the emotional stress that accompanies a caring role.
- Carers need support in prioritising their own health and well-being, as well as that of the person that they care for. Offering health checks to carers in venues that are easily accessible and at appropriate times can help, as can the provision of a sitting service and flexible health appointments so that carers can attend clinics and/or general practices and do not neglect their own health.

8. Involvement and engagement

8.1 Introduction

Involving carers in the design and delivery of carers' services can help to ensure that provision best meets the needs of those it is designed for. Consultation with carers, and their engagement and involvement in decision making bodies, discussion forums, or in service delivery is clearly beneficial to stakeholders because it makes them more aware of carers' needs and therefore provides the opportunity to respond to those needs more effectively. Again evidence from the evaluation of the National Carers' Demonstrator Sites programme showed that some of the most effective services were those which had involved carers in the design and/or delivery (Yeandle and Wigfield, 2011b). This section looks at the perceptions of carers on the extent to which carers in North Lincolnshire are currently involved in service provision and support. It explores: how and in what ways carers are involved; how this involvement benefits carers; and the extent to which carers wish to be involved in this way. Specific topic areas raised with carers and stakeholders in the consultations focussed on: the involvement of carers on project boards/carer task groups/steering groups; using carers as evaluators of services; involvement in carers' forums; consultation events or workshops with carers; hosting of local events, including those for the annual carers' week.

8.2 Availability of opportunities for consultation, carer involvement and engagement

Some opportunities do exist for involvement and engagement by carers in service provision and delivery in North Lincolnshire, and there are opportunities for carers to take part in consultation activities. These opportunities primarily centre on involvement in the Carers' Support Centre at Brigg, and involvement in support groups.

The Carers' Support Centre is a charity; its board, including the Chair and Vice Chair, is comprised mainly of carers. The board is involved in service delivery and attend staff meetings. The Carers' Support Centre management, and some carers associated with it, are also key participants in the Carers' Advisory Group (a group which is organised by NHS North Lincolnshire, meets once a month in Brigg or Scunthorpe, and is described by them as 'The voice for adults who care for adults who have a physical or mental illness, are elderly, frail or disabled in North Lincolnshire'), alongside other stakeholders including NHS North Lincolnshire and North Lincolnshire Council. The Carers' Support Centre views this involvement positively, and believes that the Carers' Advisory Group has some influence over services and how money is spent. The Carers' Support Centre, therefore, presents opportunities for some carers to have an involvement and engagement in service provision and delivery.

Carers in North Lincolnshire who are involved in support groups, either the 14 organised by the Carers Support Centre in Brigg or those that are organised independently of it, greatly appreciate the peer support that it provides them with.

One carer explained the importance of a support group to her:

'It was really valuable, better than anything else. Suddenly you find another carer. It makes you feel safe. You feel that you are the only person dealing with this problem. You get into a group and someone says: oh, mine does that. It's not just your son or daughter that's not normal.'

North Lincolnshire carers are also represented in decision-making bodies in more indirect ways. Carers are represented by Rethink, for example, on a monthly collaborative meeting chaired by a service user, run by a local NHS foundation trust, along with other health care

stakeholders such as NHS managers and patient/carer groups. This local NHS foundation trust states that carers are involved in setting the agenda for these meetings and that there is a user/carer partnership council across the whole trust relating to mental health care, and that carers set markers through this mechanism for quality and improvement. The issues raised at these meetings provides information on which negotiations with commissioners can be based, or which lead it to highlight issues to local authorities, for example, if support provision for carers is inadequate. Again at an indirect level, the local NHS foundation trust referred to above states that it has frequent contact with the Carers' Support Centre, and always offers opportunities to the Centre to be involved when this is appropriate.

8.3 Perceptions of carers' consultation, involvement and engagement

Some carers said in focus groups that they thought they were listened to more than they had been in the past, though at least as many carers did not share this view, and thought that their voices were not heard or, if they were, they felt they were being ignored. Some carers, the majority of those expressing a view, were not interested in becoming further involved or engaged. This kind of involvement was seen by some as time consuming and, in some cases, caring responsibilities were such that carers could not become further involved or engaged even if they wished to. A high proportion of the carers who were spoken to as part of the consultation expressed cynicism that such activities had any impact.

If carers are to be involved in service design and delivery they need to be provided with opportunities for meaningful involvement and engagement including opportunities for participation in consultation activities. This is beneficial to carers generally, beneficial to those carers who are able and willing to participate, and beneficial to stakeholders because it enhances their awareness of carers' needs.

8.4 Summary

The perceptions of the carers and stakeholders who were consulted for this research can be summarised as follows:

- The involvement and engagement of carers is beneficial to carers generally, and is useful to stakeholders and policy makers as it makes them more aware of, and potentially receptive to, carers' needs in designing service delivery and formulating policy.
- There are some opportunities for carers in North Lincolnshire to become involved and engaged in service provision or delivery, or to participate in consultation activities. Primarily, this is through the Carers' Support Centre in Brigg, through involvement in their support groups or engagement with the Centre in some other capacity; or through support groups operating independently of the Centre, such as the Alzheimer's Society, Empathy, MIND or Rethink. Those carers who are involved in support groups greatly appreciate the groups and the benefits that they bring to them.
- There are also some opportunities for more limited, indirect representation on decision-making bodies through a local NHS foundation trust.
- Many carers benefit strongly from their association with, or involvement in, the Carers' Support Centre.
- There are many carers, however, not involved with any of these organisations or groups. Support, in whatever is the most appropriate way, may not be reaching some of these carers who are not involved. Attempts should be made to reach these as well.

- Carers' perceptions on whether they were listened to more now than they had been in the past differed. Some believed that they were consulted now and listened to more than they had been in the past. At least as many, however, thought exactly the opposite: that they were not listened to now and never had been.
- It should be recognised that a significant proportion of carers said that they do not want or have the time for any further involvement or engagement.

9. Conclusions and Policy Recommendations

This research project has demonstrated that there are growing numbers of carers in North Lincolnshire, as there are in the UK overall, and that this pattern is set to continue in the future. Carers provide a valuable service both to those that they care for, but also to the health and social care system. Caring, although rewarding, is also a challenging activity and carers require support in many aspects of their lives. They require support to access information and advice about their caring role, the rights and entitlements of the people they care for, and the rights and entitlements of they themselves as carers, including the availability of state benefits. They require breaks and other forms of support that can enable carers to have a life of their own, and help them to maintain their health and well-being, such as health checks and access to medical appointments. They require education, training and employment support, so that carers can obtain relevant skills and knowledge to continue in, or return to, paid employment when their caring role allows. A number of conclusions can be drawn from the findings of this research, each of which requires appropriate policy interventions:

Carer identification

Many carers in North Lincolnshire, as elsewhere in the UK, do not recognise themselves as carers, and are not identified as being carers by the health and social care system. If carers are to be reached so that support services can be made available to them, they need to be identified both by themselves and by the health and social care system. Evidence from this research and a review of good practice elsewhere indicates that a number of strategies can be effective to help increase carer identification and these should be adopted wherever possible in North Lincolnshire

Policy Recommendation 1: Partnership working between the health, social care and voluntary and community sectors should be encouraged. This is a successful way to improve carer identification and the voluntary sector is particularly effective in reaching wider groups of carers such as minority ethnic carers. Expensive marketing strategies such as leaflets and posters are not always effective in reaching 'hidden carers' and use of more cost effective alternative strategies should be encouraged, for example by health and social care professionals identifying and engaging face-to-face with carers when they accompany the person being cared for to medical appointments at general practices, clinics, hospitals. This should be supported through training for all health and social care professionals who are likely to come into contact with carers, so that they are aware of the needs of carers and so that they signpost carers to the services that are available to them. Positive examples that are being used elsewhere include a yellow card GP referral system operated by Carers Leeds (Carers Leeds, 2011/12), volunteer Carer Ambassadors - a scheme run by Carers UK - who are operating around the country, and GP Champions who are also operating in localities around the country initiated by the Royal College of General Practitioners (RCGP) (Wigfield and Wright, 2012).

Information and advice

The provision of timely information and advice, that can be easily accessed, is crucial to carers. To reach the maximum numbers of carers, information and advice services need to be presented to them in different forums: through websites, telephone help lines, face-to-face, through brochures, leaflets and posters. As is the case with carer identification, information and advice needs to be *taken to* carers and presented *pro-actively*, as many carers have a low awareness of where and how to access basic information. The Carers' Support Centre in North Lincolnshire is currently providing an information and advice service which is greatly valued by carers.

Policy Recommendation 2:

The Carers' Support Centre should be supported to continue to offer the information and advice services that it currently does and this service should be targeted at a wide range of carers across the whole of the sub-region. Health and social care staff at NHS North Lincolnshire and at North Lincolnshire Council should be encouraged to liaise closely with the Carers' Support Centre at Brigg in order to assist in the dissemination of information and advice to all carers that they come into contact with. To ensure that existing services are built upon and not duplicated, therefore providing a cost effective way forward, once carers are identified, they should be asked to register as a carer with the Carers' Support Centre and sent a carer's information pack, containing information for carers. The pack should contain information on: the availability of benefits, advocacy, the support available for carers; contact details of support groups and organisations; details of telephone help lines; the services provided by organisations such as NHS North Lincolnshire, North Lincolnshire Council and so on; the support available for the person being cared for; and medication. All the information contained in the pack should be replicated on relevant websites (where it is not already) that carers might consult. To ensure that the information is accessible to all carers it should be available in different community languages.

A poster could be used to accompany the information pack and should be distributed to all venues where carers might see it: Local Link Offices; libraries; supermarkets; community notice boards; advice centres; churches and other places of worship. It is essential, however, that such a poster campaign does not take place in isolation but accompanies the direct contact suggested in recommendation 1. Evidence shows that leaflet and poster campaigns directed at carers are not successful without accompanying face-to-face contact and support. Both the information pack and poster campaign should aim to raise carers' awareness of the potential availability of Carer's Individual Payments, which many carers in North Lincolnshire appear to be unaware of.

Carers' breaks

Evidence from evaluations of breaks services for carers across the country demonstrates that a short break from the caring role can help carers to maintain their health and well-being and avoid carer breakdown. Although there is support for carers in North Lincolnshire to access breaks, through the provision of Carer's Individual Payments and grants for breaks through the Carers' Support Centre, many carers remain unaware of the support available for breaks. Carers in North Lincolnshire have suggested that they would very much welcome greater availability of access to breaks from their caring role, although some are concerned about the cost associated with a breaks service and others are reluctant to leave the person being cared for and have concerns about the quality of alternative or respite care provision. Some groups of carers have particular concerns relating to alternative or respite care. This includes ethnic minority carers, for example, who fear that the person being cared for will not be looked after in a way that meets the cultural norms within their own community; carers of people facing mental health challenges because the cared for person may have specific requirements relating to continuity of care; and carers of alcohol and substance users where the cared for person can be reluctant to agree to alternative care arrangements.

Recommendation 3

Information relating to how carers can access a break from their caring role should be provided in the information booklet (referred to above), and all health and social care professionals should be made aware of the support available to carers so that they can signpost them to appropriate support, including breaks services. Breaks services should be made as easy to access as possible, and encompass a flexible definition of a break. Options that have worked well elsewhere, which could be developed and expanded in North Lincolnshire, include: general practitioners prescribing a break for a carer; breaks which can be booked on-line through a dedicated website; funding for whole family or individual carer

breaks (with or without the person being cared for); funding for domestic support to free up some time for the carer to spend on themselves; funding for wellness services such as gym membership, or a massage; funding to purchase one-off items of equipment, such as a bicycle, so that the carer can gain regular exercise, or a laptop, so that the carer can keep in touch with friends through social networking sites. Provision of day care services for some groups of persons being cared for, particularly those with dementia, have also had a positive effect on carers in some parts of the country. Particular attention should be paid to the alternative care offered whilst the carer takes a break, to ensure that it is tailored sufficiently to meet the needs of the person who is being cared for with respect to ethnicity, religion and so on.

Supporting carers' education and training needs

The provision of support for carers in relation to education and training is important because it can help carers to pursue their own aspirations beyond caring, thereby contributing to the achievement of one of the key objectives set out for carers in *Is knacarered a Medical Condition?* which stated that, by 2011, carers in North Lincolnshire would '*be able to have a life of their own alongside their caring role*', an objective which is also outlined in the National Carers' Strategies (H.M. Government, 1999; 2008; 2010). Some carers have accessed the Caring with Confidence course and those who have were very positive about the programme. Most carers in North Lincolnshire, however, are unaware of what support is available in relation to education and training. Moreover, primarily due to time constraints, there appears to be little demand among the carers that we consulted for education and training, apart from that which helps them in their caring role, for example in personal care, and in understanding specific medical conditions, particularly in relation to mental health issues, where both stakeholders and carers believe there are gaps in provision. It is particularly important to provide flexible education and training provision for young carers, and simple measures can be adopted by schools and colleges to cater for their needs. However, the extent to which schools and colleges are adopting these measures is not entirely clear. As with many other areas of support potentially available to carers, there is a significant lack of awareness among many carers in North Lincolnshire of help that is available in relation to education and training, and there is a need for flexibility in terms of the time and venues of the provision.

Recommendation 4

Existing education and training programmes and services – provided by the Carers' Support Centre at Brigg and by North Lincolnshire Council – should be publicised more effectively, through the information booklet (recommended above) and through a variety of means, including websites, and through poster displays in a range of venues such as Local Link Offices, libraries, supermarket notice boards, advice centre notice boards, general practices, hospitals, hospices and clinics. Again, health and social care professionals, and those working specifically with young people at schools and colleges, should be made aware of the provision and be encouraged to disseminate this information to young carers in particular.

Existing support should continue to be provided through Lifelong Learning activities, and through the Caring with Confidence programme at the Carers' Support Centre. Any education or training sessions need to be provided in a way that is flexible enough to allow carers to access them. A practical guide of the key requirements that training programmes for carers need to incorporate was produced as a result of the evaluation of the Caring with Confidence programme (www.circle.leeds.ac.uk/projects/completed/supporting-carers/evaluation-of-the-caring-with-confidence-programme/), and these key requirements should be taken into account when designing and delivering training programmes. Staff at schools and at colleges of further and higher education should be encouraged to facilitate the identification of young carers, understand their needs, and signpost them to relevant support, to ensure that they can continue with their education whilst caring.

Supporting carers to remain in or return to employment

Carers in North Lincolnshire told us that a sympathetic and flexible employer is a crucially beneficial factor in allowing them to continue in paid employment. Other carers benefit from family support, but some carers have neither of these support mechanisms and consequently struggle to remain in paid employment. We also know that early intervention and support in assisting carers to remain in employment is often effective, and that once carers have left the paid labour market it is much more difficult to help them to return. However, there appears to be very little specific tailored support available to carers in relation to trying to find paid employment, or to support those carers who are in paid work.

Recommendation 5

Various mechanisms have been introduced elsewhere to assist carers to enter, or return to, paid employment and some of these could be introduced in North Lincolnshire, perhaps initially as pilot schemes. Three strands of support have been identified which could help support carers to remain in, enter, or return to paid employment in North Lincolnshire. The first strand could be working with local employers. Employers for Carers (EfC) is a service for employers aimed at helping them retain their carer employees by promoting the business benefits of supporting carers, and by providing advice and support on carer friendly policy and practice (www.employersforcarers.org). Representatives from EfC could be invited to an event designed for the large North Lincolnshire employers, including NHS North Lincolnshire and North Lincolnshire Council. This would enable employers to understand the importance of supporting the carers in their workforce, and provide them with information on the kinds of strategies that they can put in place to do so. The second strand could be the development of a specific, locally based, initiative to support carers into employment. Employment support projects for carers have been successfully implemented in other parts of the country, often being run by the local authority or by a local carers' centre, to provide activities for carers such as CV writing, confidence building skills, assistance with setting up in business or in self-employment, and North Lincolnshire Council and the Carers' Support Centre at Brigg could collaborate to develop such an initiative. The third strand could be centred on providing alternative care for the cared for person so that carers themselves can engage in paid work. Various initiatives have been adopted elsewhere which could be drawn upon in North Lincolnshire, including a sitting service using volunteers, a buddying or befriending system, and more widespread use of telecare and/or telehealth in the homes of the person being cared for. A buddying system is already being operated by Humbercare which could be replicated for provision in North Lincolnshire.

Carers' health

Many carers are under considerable emotional stress which presents a challenge to their physical health and emotional well-being, and yet carers can sometimes neglect their own health because of the challenges of their caring role. Both stakeholders and carers in North Lincolnshire have suggested that carers need support in prioritising their own health and well-being, as well as that of the person that they care for. Evidence from research and evaluations elsewhere has shown that offering health checks to carers in venues that are easily accessible, and at appropriate times, can help, as can the provision of a sitting service and flexible health appointments so that carers can attend clinics and/or general practices and do not neglect their own health. Having short breaks from the caring role can also help maintain carers' health and well-being and avoid carer breakdown.

Recommendation 6

The health-related activities currently taking place at the Carers' Support Centre – through the health liaison workers, the advocacy service, the counselling and breaks provision – should continue to be supported. In addition to this, health checks should be offered to all carers through general practices and, if demand for these health checks in rural areas is sufficient, where transport is poor and there are few or no general practices, NHS North

Lincolnshire should explore the possibility of offering these health checks through some other means, such as mobile units, or in local community facilities. Consideration should be given to training local third sector representatives to deliver the health checks under the supervision of clinical staff. A renewed effort should be made to remind general practice staff and other health and social care professionals of the need for flexibility in relation to appointments and meetings when dealing with carers and, where possible, a sitting service should be offered so that the carer can attend their own medical appointments. Another possible policy option for NHS North Lincolnshire is to launch an attempt to help carers maintain their own health, focusing particularly on alleviating stress and drawing on complementary therapies. This could involve a holistic programme drawing on counselling, hypno-therapy, Reiki, Indian head massage, Shiatsu massage, reflexology, auricular acupuncture, relaxation. This could be offered at a central location, in Brigg or Scunthorpe or both. For carers able to get to these locations, a sitting service could be offered where necessary to allow the carer to attend. For carers who cannot attend, or do not wish to leave the cared for person, this service could be offered on an outreach basis, with people delivering the service visiting the homes of the carers. Some of these techniques were deployed successfully in a project designed to help users of drugs and alcohol in 2008 in Burngreave, Sheffield, for example.

Involvement and engagement of carers

Involving and engaging carers in both the design and delivery of carers' services provides capacity building benefits to those carers who are involved, and enables stakeholders and policy makers to ensure that services are receptive to the needs of carers. There are some opportunities for carers in North Lincolnshire to become involved and engaged in service provision or delivery, and/or to participate in consultation activities. Primarily, this is through the Carers' Support Centre in Brigg, through involvement in their support groups or engagement with the Centre in some other capacity; or through support groups operating independently of the Centre, such as or the Alzheimer's Society, Empathy, MIND or Rethink. Those carers who are involved in support groups greatly appreciate the groups and the benefits that they bring to them. There are also some opportunities for more limited, indirect representation on decision-making bodies in North Lincolnshire through a local NHS foundation trust. It should be recognised that not all carers want to be involved in the design or delivery of services and a significant proportion of carers who were consulted for this study said that they do not want, or do not have the time, for any further involvement or engagement.

Recommendation 7

A panel of carers should be established who are broadly representative of carers in North Lincolnshire in terms of age, gender, the amount of caring they carry out, their employment status, the nature of their caring role, and the condition of the person that they care for. This panel should be provided with appropriate training and consulted about the potential impact of new initiatives and services for carers. Additional opportunities for carer involvement and engagement should continue to be provided for those who wish to participate through: the Carers' Support Centre at Brigg; carers' support groups, organised by the Centre and independently of it; consultative forums and similar bodies organised by NHS North Lincolnshire or other NHS bodies; and North Lincolnshire Council.

Aligning recommendations with existing provision

There is some existing provision for carers in North Lincolnshire through the Carers' Support Centre at Brigg, which is perceived positively by many carers. Some of its services are strained, however, because of resource limitations, and there needs to be enhanced capacity to deliver a wider range of services covering all parts of North Lincolnshire, especially rural areas. North Lincolnshire Council and NHS North Lincolnshire are also delivering some services to support carers.

Recommendation 8

In developing and implementing the recommendations outlined above, there is a need to align new provision with existing services and to deliver this through integrated work involving the health and social care sectors, the Carers' Support Centre, and other voluntary sector organisations. Resources need to be directed to this integrated provision, with a view to filling gaps and extending the reach of services to all parts of North Lincolnshire, especially rural areas.

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Appendix 1

Stakeholder telephone interviews were held with representatives of the following types of organisations:

Children's charity

Carers' support organisation

Two representatives of different mental health support groups

Three local authority representatives

Neurological illness support group

An NHS foundation trust

Large private sector employer

Voluntary sector representative