North of England
Mental Health Development Unit

Gateshead Carers Association
Reaching Hidden Carers Project

An External Evaluation Report

April 2014
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Executive summary

New estimates show that there are over 6 million people in the UK providing unpaid care for ill or disabled loved ones. However, many carers do not identify themselves as carers, and many carers do not access services or support; these carers are known as “hidden carers”. Without the right support the personal costs of providing this care can be high, with at least 8 in 10 carers seeing a negative impact on their physical and mental health.

In a project commissioned by the BIG Lottery Fund, Gateshead Carers Association (GCA) set out to identify these “hidden carers” and help them benefit from the services available to them.

This report, commissioned by GCA, seeks to establish the extent to which their Hidden Carers project has succeeded in achieving its intended outcomes and has involved:

- a review of the project’s services
- analysis of the service’s outcome data
- interviewing an opportunity sample of previously hidden carers and local employers who have accessed GCA services as part of the new project

Outcome 1

Over 700 previously ‘hidden’ carers will have improved health and well-being as a result of the reduction of stress caused by their caring role and increased access to information, advice and guidance by the end of the project.

Through this evaluation, it was found that in the 30 months since this 36 month project began, GCA have dramatically increased their ability to liaise and work with the wider community in promoting the needs of carers and the support available to them, thereby increasing their ability to reach hidden carers.

- The GCA project has succeeded in identifying, advising and supporting a total of 724 previously hidden and hard to reach carers.

- Carers interviewed as part of the evaluation study said that the support they received from the Working Carers project had positively impacted upon their health and wellbeing.

- GCA have been very successful in reaching almost triple the BAME community (11%) as a percentage of the overall Gateshead population (2011 Census estimated BAME community in Gateshead at 3.7%).

- Data from the project suggests a very positive change across all 5 aspects of the lives of carers based on the outcome measures used.
Outcome 2

A minimum of 18 Gateshead based employers will have a better understanding of the problems and stresses faced by carers which will lead to the adoption of carer friendly employment policies for over 6000 employees (600 carers based on 2001 census) by the end of the project.

By establishing links with local employers, social events, Gateshead’s Black, Asian and Minority Ethnic (BAME) community, GCA have succeeded in reaching out to a large number of employers, in addition to the 18 employers they directly worked with as part of the project, using the Carer Friendly Charter. They have also succeeded in setting up a large range of support services in order to identify, advise and support carers in the borough.

- The GCA Hidden Carers project has both met and exceeded its goals in this area. They have directly engaged with 18 employers in Gateshead, encouraging carer friendly employment policies and giving access to GCA services to over 25,000 employees (approximately 2500 carers, based on 2011 census estimates).

- When employers were asked to rate their satisfaction with the input/services they had received, on a 10 point scale (where 1=’not at all’ and 10=’totally satisfied’), GCA received an average score of 9.4.

- 100% of the employers said that they would be “extremely likely” to recommend Gateshead Carers services to employees or other organisations if they need advice or help.

- The successful engagement and work with local employers has led to further initiatives that have brought added value to the project, such as the NE Working Carers Tool-Kit, which has led to GCAs efforts being recognised on a regional scale, promoting carer support services to a potential 100,000 working carers.

Outcome 3

A minimum of 100 carers will have short breaks from their caring responsibilities, resulting in increased confidence and carers being more able to cope with their caring role by the end of the project.

The project has included the development of a variety of Short Break Groups, designed to help carers focus on their own needs and work on developing personal skills and interests.

- The short break activities have been received incredibly well by carers with nearly three times (264) the original target figure already reached and still a further six months of the project to run.

- Feedback from participants of the Short Break Plus activities clearly demonstrates benefits to those attending across the full range of measures, with the vast
majority of respondents either agreeing or strongly agreeing that the activities had a positive impact.

- The narrative feedback in particular highlighted the value of these groups in combating isolation with a number of carers citing the value of being with other people.

GCAs work to promote awareness of the problems and stresses faced by carers in the workplace is further reflected in the fact that GCA has been selected as Charity of the Year 2014 by Sainsbury’s. Such recognition is important for the continuation and expansion of projects such as this one, with the charity relying on donations and funding to support free services to carers. GCA will use this opportunity to raise awareness of unpaid carers and to promote the hidden carers support service across the region.

It is clear that GCA have not only met, but exceeded, their intended outcomes. Feedback from both employers and the carers themselves demonstrates the high value placed on this service by those using it. Similarly both employers and carers would highly recommend this service to their peers.

Having reviewed the potential for this project to be not only continued, but expanded, this report then offers areas for future consideration:

- Build on the success of working with large employers to develop specialist support for smaller organisations
- Develop a programme of outreach drop-ins at public locations to identify working carers
- Monitor any changes in the number of people dropping out of work before they seek help as an indicator of raised awareness of GCAs services in the workplace
- Develop further specialist carers support for BAME communities
- Develop the role of Carer Champions within workplaces
- Focus on identifying, engaging and supporting male working carers
- Increase use of the innovative outcome measurement tool
- Identify funding/resource opportunities to maintain and build on the success of this project.

It is estimated that by 2017, the population of the UK will reach a tipping point for care, where the number of older people needing care will outstrip the number of working age family members currently available to meet demand.

It is vital that this project continues to provide carers with the support they need to sustain their caring role, without impacting negatively upon their work, health and wellbeing: the kind of information, advice, and support provided by GCA will continue to be invaluable.
1. Service Context

“Most of us will look after an elderly relative, sick partner or disabled family member at some point in our lives. The 2011 Census figures for England, Wales and Northern Ireland show an increase in the number of carers since the last Census in 2001, from 5.22 million to 6 million, an increase of 629,000 people who are providing care in only 10 years.” (Carers UK; facts about carers, 2012).

It is estimated that these Carers save the economy £119 billion per year (an average of £18,473 per carer) that would otherwise be needed to pay for the support they provide for their dependents. In addition, over 3 million carers further contribute to the economy and their communities by balancing their caring responsibilities with full or part-time employment.

The 2014 survey of Gateshead Carers has identified that:

- The biggest change in the period is the number of respondents describing themselves as unemployed which is up from 7% in 2011 to 15% in 2014.
- The biggest change in the age range of carers responding to the survey was in the 51-65 years age group which increased from 30% in 2011 to 47% in 2014 (ie. Working age carers)
- In the past 12 months 50% of respondents said that their caring role had caused them financial difficulties. Of those, 20% have had to give up paid employment compared to 10% in 2011.
- 13% of respondents felt that they had reduced promotion/training opportunities at work because of their caring role compared to 7% in 2011.
- The greatest reported change (from 17% in 2011 to 54% in 2014) was in the number of respondents who had to use their own money and savings to pay for equipment and services for the cared for.
- Overall 69% of carers reported their health as ‘average to very poor’. This compares to 58% in 2011.
- In 2011, 58% of carers said their health was worse as a result of their caring role. This has increased to 74% in 2014.
- The biggest reported increase was related to the caring role having a negative impact on carers’ mental health and wellbeing which registered as 16% in 2011 and 43% in 2014.

However, as these statistics rely on carers identifying themselves, it is believed that the actual number of carers in the UK may be far greater. Known as “hidden” carers, there are many reasons why some people might not readily identify themselves as being in a caring role. It is felt that many feel that they are simply carrying out ordinary responsibilities as a family member or friend: “looking after” a dependent rather than being their “carer”. For example, research shows that many carers of children with learning disabilities may continue that caring role into their child’s adulthood and as such do not see themselves as carers but simply as parents. Carers of people with stigmatised conditions (e.g. mental health problems, drug and alcohol problems) may be reluctant to make their needs known. Finally of course, for some people in a caring role it may simply be that they do not see themselves as being in need of external help or services.
Black, Asian and Minority Ethnic (BAME) Carers appear to be a particularly hard to reach group. They are less likely to receive additional support from their GP around caring, more likely to miss out on financial support and more likely to be caring without any practical support from services or friends and family (Carers UK; State of Caring Survey, 2011).

The main concern surrounding the existence of “hidden” carers is that without the right support the personal costs of providing care can be high. Joint research published by the Carers Week Charities (In Sickness and in health; a survey of 3400 UK carers about their health and well-being, 2012), shows that at least 8 in 10 carers have seen a negative impact on their physical and mental health as a direct consequence of the stress and physical demands of their caring role. Carers attribute this health risk to a lack of adequate support, with 64% citing a lack of practical help and 50% a lack of financial support, as the cause of their poor health.

As many as 1 in 5 UK adults have seen their work negatively affected as a result of caring, with many reducing working hours or leaving employment entirely (Carers UK, 2011). Of these, a fifth lost around £10,000-£15,000 of their yearly income, with a further fifth being £15,000-£20,000 worse off. Older working carers (aged 55-64) were likely to suffer a drop in income of at least £30,000 when they took on greater caring responsibilities, reflecting the fact that many were leaving skilled and/or senior positions at the peak of their career (Carers UK, 2011). Such sacrifices have clear implications for a carer’s sense of wellbeing, independence and financial security: causing debt and long-term damage to careers and pensions.

As well as the personal impact that leaving work has for the carers, their families and the cared-for, the assumed impact on employers can also be significant: with increased staff turnover, recruitment and training being among the main costs. Previous estimates also indicated that the cost to the economy of carers being forced to give up work to care had reached £5.3 billion in lost tax revenues and earnings and additional benefit payments (Age UK, 2012). Even from a purely productivity focused perspective, the importance of promoting health and wellbeing among working carers is high on the Government’s policy agenda.

Gateshead Carers Association (GCA) is an independent charity and network member of The Carers Trust. They are currently funded through various streams including Gateshead Clinical Commissioning Group, Gateshead MBC and the Big Lottery Fund as well as through private donations from individuals. They work to ensure that;

- Carers have increased choice and control in their lives
- Carers have improved health and well being
- Carers are treated with respect and dignity and their role is recognised and valued
- Carers have a life of their own outside of caring and
- To campaign for and on behalf of carers.

It is worthy of note that GCA has seen an 82% increase in demand for its services in the last 12 months.
In July 2011, GCA received a three year grant from the Big Lottery Fund to identify and support previously “hidden” carers from hard to reach groups across Gateshead, offering choices and control for carers, helping to give them more independence, and enhance their health and wellbeing.

The past experience of GCA has been that working carers in particular have been under-represented among the population that use their services. GCA believe that this was because these people either did not recognise themselves as carers, or were unaware of the support and services that were available to assist them in this role. Also, GCA identified that within BAME communities, parents of children with disabilities appear less likely to identify their caring responsibilities as separate from their role as a parent.

A survey carried out by GCA in August 2010, showed that 72% of carers felt it would have been advantageous to have known earlier about the services GCA provides. Therefore, in order to reach hidden carers such as these, GCA intended to concentrate on the use of promotional materials and awareness raising activities as the means by which they communicated their ability to promote the needs of carers and the support available to them. They aimed to achieve this by working with:

- Existing networks of local community groups operating in Gateshead neighbourhoods, including BAME, Faith groups, and schools providing support for special educational needs
- Gateshead Carers Partnership (a number of local charities and statutory agencies)
- Healthcare professionals, hospitals and GP practices

In order to identify hidden working carers, there was also a particular focus on developing and launching a Carer Friendly Employers Charter (see Appendix G) to create links with local businesses and helping them recognise and support carers within their workforce. This aspect of the project would also involve the creation of a new Support Worker role, in order to provide support and access to services to working carers once they had been identified.

A further aim of the project was to provide short breaks ‘plus’ for carers. Respite for carers is vital in helping them to maintain their own health and wellbeing, whilst supporting them in their caring role. Consultation was carried out with carers to provide a range of activities that would help provide a break from caring and also help to decrease social isolation, improve skills and help carers to have a life of their own. These sessions included social groups, specialised BAME support groups, LGBT support groups, a men’s group and support for parents with disabled children.

It was GCA’s stated objective that through the Hidden Carers Project, they would be supporting carers from all neighbourhoods of Gateshead and in all communities by September, 2014. The project as a whole was to be co-ordinated by a Development Manager within GCA, and other staff members and volunteers were expected to contribute time to this project as and when roles overlapped or support was required.

The following sections of this report are concerned with illustrating the services that have been developed; establishing the extent to which the work of the Hidden Carers project has succeeded in achieving its intended outcomes; and future areas for consideration.
2. Methodology

To describe and evaluate the ways in which the grant from the Big Lottery Fund has been used to implement and improve services for carers, this evaluation focuses upon establishing whether three service-outcome goals (set by Gateshead Carers at the beginning of the project) have been reached. Specifically that:

1. Over 700 previously ‘hidden’ carers will have improved health and well-being as a result of the reduction of stress caused by their caring role and increased access to information, advice and guidance by the end of the project.

2. A minimum of 18 Gateshead based employers will have a better understanding of the problems and stresses faced by carers which will lead to the adoption of carer friendly employment policies for over 6000 employees (600 carers based on 2001 census) by the end of the project.

3. A minimum of 100 carers will have short breaks from their caring responsibilities, resulting in increased confidence and carers being more able to cope with their caring role by the end of the project.

Evaluating the service against these outcomes has involved:

- A review of the project’s systems and services in application, including an overview of the roles of staff members involved in the project.

- Analysis of the service user demographic and outcome data, collected internally by GCA as part of service delivery.

- Interviewing an opportunity sample of previously hidden carers who have accessed GCA services provided as part of the new project.

- Interviewing an opportunity sample of employers who have accessed GCA services provided as part of the new project.
3. Service delivery and outcomes

Between November 2011 and March 2013, GCA records show that a total of 724 previously hidden and hard to reach carers have been identified and offered information, advice and support as part of this project. 585 (81%) of these were identified and supported through the “Working Carers” service, with a further 139 (19%) being identified and supported by GCA through those aspects of the service designed specifically for BAME carers.

This means that within the first 30 months of this 36 month project, GCA have already exceeded the project’s target of reaching 700 hidden carers.

The characteristics of the individuals identified and supported through the “Working Carers” service were as shown in the following figures.

NB. Figures 1 – 4 represent between 35-40% of the 585 working carers identified and supported.

**Figure 1: Ethnicity of working carers**

- African - Black Or Black British
- Chinese
- Indian - Asian Or Asian British
- Other Ethnic Group
- Pakistani - Asian Or Asian British
- White - British
- White - European

Figure 1 shows that GCA have been very successful in reaching almost triple the BAME community (11%) as a percentage of the overall Gateshead population (2011 Census estimated BAME community in Gateshead at 3.7%).
Figure 2: Age range of working carers

Figure 2 demonstrates that the project is reaching its intended audience of working age (18-65 years) carers (96%) with a very small percentage being outside of this age group.

Figure 3: Gender of working carers

Figure 3 reflects the national trend where there are more female carers than male, however national figures (NHS Information Centre for Health 2010) reflect 58% female carers and 42% male. GCA have identified this as an area for future focus to reach hidden male carers in the workplace.
As may be anticipated, Figure 4 shows that 89% of the carers working in Gateshead reside within the Gateshead area, with a further 11% living in neighbouring areas and commuting into Gateshead to work.

The characteristics of the 139 individuals identified and supported by those aspects of the service designed specifically for BAME-carers were as shown in Figures 5 – 7 below:

Figure 5 demonstrates the success of GCA in engaging with BAME carers, including some minority groups who GCA have not previously worked with. It is worthy of note that staff from Gateshead Metropolitan Council have used this successful engagement with BAME communities to support their own consultation activities.
Figure 6: Age ranges of BAME carers

- 18-29 years: 13%
- 30-49 years: 24%
- 50-69 years: 41%
- 70 years +: 8%
- Unknown/undisclosed: 14%

Figure 6 demonstrates the project is reaching its intended audience within the BAME community, with a good representation from all adult age groups.

Figure 7: Areas in which BAME carers reside

- Central Area (Bridges, Bensham and Saltwell): 52%
- East Area (Felling, Deckham): 22%
- Inner West (Teams, Dunston): 16%
- South Area (Low Fell, Birtley): 4%
- West Area (Blaydon, Ryton, Whickham): 2%
- Unknown/undisclosed: 4%

We can see from contrasting figure 7 with figure 8 that GCA have been extremely successful in engaging with representative number of members of the BAME community within each of the identified wards. (Figure 8 below shows the percentage of Gateshead’s BAME population by wards: Census 2011 Ward Factsheets, www.gateshead.gov.uk.)
59 of the 139 previously hidden BAME carers (just under 42%) were referred to a GCA support worker following their initial contact. 38 (27%) of the BAME carers attended GCA training, including sessions specifically tailored to meet needs of BAME groups (i.e. run with interpreters). These sessions were:

- Carers Rights Training for Polish Carers Group
- Carers Rights Training for Pakistani and Bangladeshi Women’s Group
- Dealing with Stress Training for Polish Carers Group

In order to reach this number of previously hidden carers, the GCA project has evolved since its inception to include a large number of different services and activities, all geared at identifying and then supporting hidden and hard to reach carers in the Gateshead community, some of which are detailed below.

3.1 Information sessions

During the period of the project GCA have held 28 community based, 16 evening and 8 weekend sessions, giving information and advice to carers.

GCAs records show that 86 BAME Carers attended information sessions that were provided by GCA, using interpreters and translated materials. The groups were themed on the following topics:

- Accessing Carers Allowance, Attendance Allowance and Disability Living Allowance
- Carers Assessment and Community Care Assessment
• Working Carers and Employers of Carers
• Equipment and adapting the home
• Personalisation and direct payments

This project enabled GCA to develop a range of BAME groups, such as Polish, Roma and Chinese, where information sessions were held, as well as at existing BAME groups already running within the Gateshead community (e.g. Congolese Solidarity Circle, Gateshead Muslim Society, Gateshead Visible Ethnic Minorities Support Group, Gateshead African Community Group, Kurdish Community Association).

The project workers note that the weekend sessions have proved less popular than anticipated, but also that they have been the only way that some working carers and carers from BAME backgrounds have been able to attend.

During this project GCA has also set up a Polish language email service, used to publicise or send information to Polish carers. This is linked to a page GCA has set up specifically for Polish carers, on a popular social media and networking website.

3.2 Establishing service outcomes

In order to better understand the baseline and outcome measures for their services, GCA asked carers to complete a short self-report rating scale (Appendix A). Carers rated (on a scale of 1-7, where 1=NOT AT ALL and 7=FULLY) the extent to which they believe the following 5 factors were present in their life: health and wellbeing; dignity and respect; choice and control; having a life outside of caring; and independence.

153 carers completed this measure and the data from these needs analyses has been combined here, illustrating the average ratings of this population, at the time of their first contact with GCA.
54 of the 153 carers (35%) completed this needs analysis again, after they had received some form of support from GCA. The following is a representation of the average impact that GCA support had on changing how the carers rated themselves in relation to the 5 same aspects of their lives.

The diagram above demonstrates a very positive change across all 5 aspects of the lives of carers who had received support from GCA during this project.

3.3 Hidden carers in the workplace

GCA has directly engaged with 18 employers in Gateshead. 11 of these are large organisations (having over 249 employees), 4 medium (50-249 employees) and 3 small (with less than 50 employees): giving over 20,000 employees access to GCA services through their workplace.

Awareness Raising

In order to encourage hidden carers support to access GCA services, the project workers approached over 500 organisations (mostly via mail), offering ‘Caring Awareness’ packages in the workplace (through published information or events).

Training

6 organisations have asked GCA to provide line managers with training and support on the implementation of carer friendly policies. These aim to ensure support for carers throughout an organisation, and provide advice on reducing absenteeism by supporting the working carers that they employ. This has also involved work with trade unions, establishing “Supporting Carers at Work” briefings as part of the standard training program for union stewards. This has given GCA the potential to indirectly reach an even broader population of workers and therefore, hidden carers.
Access to a ‘Carers Health Check’
During the project, 5 organisations have worked with GCA reviewing and ‘carer proofing’ their current employment policies and practice, building consideration for carers into staff recruitment and retention practices.

Support sessions
4 organisations have elected to have GCA to run a number of “drop-in” support sessions for staff. These sessions have involved GCA support workers engaging with carers in the workforce, establishing or supporting staff-carer networks and support groups (including virtual networks).

‘Carer Friendly Employers’
As part of the project, GCA also launched a Carer Friendly Employer’s Charter (see Appendix G), encouraging employers in Gateshead to sign-up to this charter in order to highlight their recognition that:

- **Carers within their workforce may require appropriate support to successfully balance work and caring commitments**

- **People who have caring responsibilities may be discouraged from seeking employment, but can play a very valuable role within the workplace**

It also seeks to encourage their commitment as employers to:

- **Showing a positive and enabling attitude to employees and job applicants who are carers**

- **Using the ‘Carer Friendly Employer’ logo in recruitment literature**

- **Ensuring line managers have information and training about supporting carers**

- **Working with GCA to support carers within the workplace and ensure employees with caring commitments are offered appropriate support.**

GCA would then accredit and work in partnership with these organisations as ‘Carer Friendly Employers’ and endorse them on their website (www.gatesheadcarers.com/services/employer-support) and give them posters and free Working Carers leaflets to display and distribute within their workplace.

13 of the 18 organisations GCA has worked with have signed up to the charter thus far: 7 large (over 249 employees), 3 medium (50-249 employees), 3 small (under 50 employees).
Added Value

All of the above work with employers resulted in the development of a Working Carers toolkit (see Appendices B-F) at the request of the Association of Directors of Adult Social Services Carers Group, designed with input from working carers and available free to employers across the North East of England. The success of these materials has led to them being adapted and distributed to Carers Centres on a regional level (giving them the materials to create support for over 100,000 working carers), and has been brought to the attention of the Minister for Care as an example of best practice.

The NE [North East] Working Carers Tool Kit comprises of:
- Employers Guide to Working Carers
- Working Carers Guide
- Information Leaflet
- Display Posters
- Carer Friendly Employer Award
- Electronic copies of all publications and an awareness raising presentation)

In order to better illustrate and evaluate some of the work that has taken place between GCA and local organisations, an opportunity sample of 6 representatives from the 18 employers were interviewed for this report. The following is a breakdown of the themes and opinions that arose from this process.

Employers were asked what they now understood to be the problems and stresses faced by working carers. Responses included:

- “At times it can be difficult for carers to fit caring duties around working hours.”
- “Employers who are not carer aware will often make demands on employees without understanding the impact.”
- Working carers have to “juggle the responsibilities of caring with the pressure of holding down a job”
- “[Working-carers] have to make hard choices. Some people would prefer to work differently (for example less hours) but cannot afford to do so without compromising something else.”
- “Due to working hours, some find it difficult to access to help and advice, support with benefits, or respite care.”
- “Recognising when they need to access help and advice – as some do not want to admit this.”
- “Support from colleagues or managers is often dependent upon an individual sharing personal or sensitive information [...] to justify different working arrangements [and] avoid criticism of ‘special treatment’.”
Employers spoke about the impact that they felt employing people with caring responsibilities had/may have on their organisation. Responses included:

- “It can be difficult to meet the needs of the carer depending on the role and the hours that they work, we try to accommodate but sometimes it isn’t always possible and this can have a significant impact on how engaged the colleague feels.”
- “[Working carers] aren’t fully engaged [in their work] as they are worrying about who they care for.”
- “Disruption in the workplace due to staff dealing with unexpected caring responsibilities.”
- “Increased applications for flexible working, increased applications for short and long term carers leave, higher absence rates.”
- “Lateness, tiredness [...] but also under performing because of other commitments.
- Some [working carers] wait until there is a crisis and they can’t cope.”
- “[Working Carers] need more flexibility in the workplace generally to balance work-life commitments, which could impact on services.”
- “Often a carer has a different perspective which means that they can offer other [staff] support and empathy.”
- “They are often very perceptive and understand how to support other carers whether colleagues or customers.”

Employers were asked what service(s) they had accessed from GCA:

- “GCA have given managers advice and information to help manage staff and services at a strategic level through work with the carers group – this can be pro-active rather than reactive. For example help reviewing policies that impact on carers – help to plan care pathways for patients.”
- “Carer friendly drop-in sessions for staff and work with HR to make sure procedures are developed that recognise the contribution that carers make.”
- “The opportunity to signpost colleagues to GCA [for 1:1 support].”
- “Staff and patients have had easier access to advice and information as the need arises. Access to face to face support individually, support groups, benefits advice, help with practical tasks or relief from caring, short and longer term.”
- “Increased awareness of carers issues through training, promotion events [and] publicity campaigns.”
When asked to rate the degree to which GCA input had been helpful to their organisation (from: no - a little - quite a lot - very much):

57% of employers said “very much”, reporting:

- “It raised awareness of services they offer to colleagues.”
- “It helped us to understand [our] colleagues’ needs and also the role of the carer.”
- “It allowed us to think about ways we can support carers more, sometimes the smallest change to a working arrangement can make all the difference to a working carer.”

29% of employers said “quite a lot”, reporting:

- “It has shown our employees that we support carers and care about what they do and the impact it has on their life inside and outside of work.”
- “Increased access to information and advice and guidance.”

14% of employers said that they were currently unable to tell, reporting:

- “Individual feedback suggests that people who access the support find it very helpful and the support for an individual in urgent need is often invaluable [...] it is very difficult to assess the extent to which this has helped the organisation.”

Employers were asked for their opinion of the Carer Friendly Employment Charter, they said:

- “The aims...[of the Carer Friendly Employment Charter ]...fitted well with the vision for the organisation, the health and wellbeing agenda for our staff, and the service we want to provide our customers.”
- “It’s a great way to support our staff and learners and also [promotes] better community engagement.”
“It’s the best way to make sure the organisation is committed to the carers’ agenda.”

“We already had a Health and Wellbeing Strategy to support the health and wellbeing of our staff. We have also worked for many years to improve the working lives of our staff – so had a lot of the policies, processes and requirements in place.”

“We support the Charter to raise awareness of the need to support carers in the workplace, and value their contribution.”

Only one of the employers interviewed had not signed the charter. The reason given for this was that, as an organisation, they “already have carer friendly policies” which they felt were sufficient to support their staff, but continue to work with GCA to improve and build upon these.

**Employers were asked to rate their satisfaction with the input/services that their organisation had received:**

On a 10 point scale (where 1='not at all’ and 10='totally satisfied’), GCA received an average score of 9.4

100% of the employers said that they would be “extremely likely” to recommend Gateshead Carers services to employees or other organisations if they need advice or help.

When asked for the main reasons for the rating that they gave, employers reported:

- “[GCA] have managed the services extremely well.”
- “I have always found Gateshead Carers to be very helpful and supportive and feel we work well together.”
- “GCA has worked with the organisation for many years, and is a key organisation that provides support to carers in our locality.”
- “We promote links [to GCA services] to staff during mandatory training.”
- “Gateshead carers have always demonstrated to us that the carer is put at the heart of everything they do, they are dedicated and passionate about making carers lives easier. This has been echoed by colleagues they have supported.”

**Finally, employers were asked to consider the impact for their organisations and/or employees, if the service(s) provided by GCA were not available. Key responses included:**

- “Gateshead carers offers a personal service to all carers, it would be a great shame not to be able to signpost colleagues to an organisation in our local community.”
- “Less support for employees [...] which would have an impact on absence and employee engagement.”
• “[It would be] likely to impact adversely on the level of information and support available to the carers locally.”
• “We are just starting to make real inroads with this work. Stopping it now would mean returning to the previous position. Fully embedding the agenda is the key to future development.”
• “We would probably have to rely on other voluntary organisations – some of which provide support for carers as part of what they do – rather than [as] their central role.”
• “The relationship we have built over the last few years means that we are able to contact [GCA] for advice and they always respond in a timely and positive manner, it would take a long time to build the same level of service or relationship with another provider.”

In summary, all of the employers interviewed felt that the interventions and services offered by GCA added value to their organisation. Part of this added value was the relationship developed between the organisations and Gateshead Carers Association over a number of years, as well as significant increases in knowledge and confidence in relation to working carers.

3.4 Direct support for working carers

Providing support for existing working carers and early intervention for carers new to their caring role, has been central to this project. As intended at the project’s inception, this involved the creation of a new support worker role. Their task was to support, advise, represent, advocate and campaign for carers living or working in the Gateshead area. As such they have become responsible for:

• Providing information and support to carers: individually and in groups.
• Representing carers and carers’ interests in its dealings with external agencies.
• Co-ordinating “Short Break” activities to give carers respite from caring (see page 22).

The most typical contact between carers and the support worker involves requests for information regarding their employment rights, such as:

• Rights to emergency leave in order to care for dependants.
• Rights to time off to attend appointments for the cared-for person.
• Rights to request alternative working patterns.
• Information about flexible working appropriate to their work role/caring role.
• Support during disputes relating to working practice, which impacts negatively on their caring roles or contribute to their carer stress. These issues require obtaining guidance from ACAS and discussing with the carer how they can try to resolve their difficulties.
• Information regarding earnings limits and carers allowance.
Other common areas of support provided to working carers in relation to their caring role include:

- Assisting with disability benefits applications, reviews and appeals.
- Referrals for social care assessment.
- Referrals for carers’ assessment (for services such as respite).
- Referrals for aids and adaptations.
- Signposting to other agencies (e.g. continence services, condition specific support groups).
- Applying for carer short break funding.
- Applying for funding for family holidays and essential household items.
- Signposting to GCA social and creative groups.
- Signposting to leisure and social activities for carers and their cared-for.
- Emotional support

The role also involves promoting awareness of working carer support, for example:

- Attending a carer forum to promote the awareness of carers in the workplace and carer friendly practice.
- Giving talks to public and private sector employers (often groups of line managers or well-being teams), promoting the aims of GCA and specifically the Working Carer services.
- Co-presenting with a DWP advisor to groups of unemployed carers about the support available to them, should they wish to return to work.
- Organising a schedule of outreach events with local employers throughout Gateshead.

Rather than providing support on a 1:1 basis at GCA premises, contact between the support worker and the working carer most typically occurs via email, telephone, or outreach visits at the carers home or place of work (either as part of a series of drop-in events arranged with employers, or by private appointment).
The following chart represents the methods by which 114 (20%) of the 585 previously hidden working carers were supported.

Providing such services means that working carers do not have to take precious time away from working or caring responsibilities in order to gain access to GCA support. The GCA support worker in this role highlighted that “...for carers that work full-time, support by email has been a successful way to provide information and emotional support” adding that these carers “have little time to navigate services” as well as “problems with privacy at work” which make face-to-face or telephone contact difficult.
Case Studies

The following case studies illustrate some of the direct support that has taken place between GCA and previously hidden working-carers. Interviewed for the purpose of this report, the names of these individuals (as well as some other identifying aspects) have been altered or omitted in order to preserve anonymity:

Catherine

Catherine is a professional who works full-time, managing a team of other professionals in a local authority organisation. Catherine cared from a distance: working full-time and travelling long distances at weekends to support and care for both of her aging parents; one of whom was terminally-ill. These circumstances elevated the stress she was already experiencing and made her caring role even more difficult. In interview for this report, Catherine recalled: "As I live quite a long way away, it was hard to find out what [support] he or I could access in their location. I was becoming increasingly stressed, trying to work and commute at weekends to support. As I have quite a stressful job I truly was wondering if I could continue to work".

Catherine therefore contacted GCA, primarily seeking information and guidance regarding local services and appropriate health care support for the specific needs of her parents. For Catherine, as well as practical advice and information, one of the most important elements of the Working Carers service appears to have been the emotional support she received from the support worker. In Catherine's words

"...they listened and understood what my parents and I were experiencing and then gave me lots of information about what and how to locate support...I was able to continue to do my job and know that my parents were well cared for and safe during the week. The level of stress I was under reduced dramatically."

Catherine also cites the accessibility of the service as being a major positive aspect of the Working Carers service, with the majority of her contact with GCA being conducted via telephone and email. This is particularly significant, as it meant she was able to access the support she needed quickly and discreetly, without her taking time away from the workplace. It was this flexible and accessible nature of service provision that Catherine described as "invaluable".

Without this support, Catherine feels that both of her parents would have been unable to remain living together in their home, or that she may have been forced to take long term leave from her job, which she expected would be extremely disruptive to her colleagues and career. Due to the positive outcomes of her interactions with the Working Carers project, Catherine has already recommended their services to friends and colleagues who are in similar positions as herself. Catherine said "I can speak with experience and I am confident that their support will help. As a manager of 70 [people], I anticipate that their support will help staff to have good wellbeing and be able to continue to work to the best of their ability, where possible."
Alexa

Alexa is a member of Gateshead’s BAME community, whom although speaks English well, does not speak it as her first language. Alexa balances her work for a large local employer, with primary caring responsibilities for a partner who developed chronic health and mobility issues following an accident.

Alexa’s working conditions required her to work varying shift patterns, and over time she began to find that this was having a growing impact on her caring role: “I was coming home very late and my working hours were always changing. My employer was always changing the rota. They knew I was a carer, but they did not seem to think about this […] I was never asked when they change [sic] my shifts [and] this made it very hard, very stressful to go to hospital and appointments with my husband.”

Alexa felt that her caring role was not taken seriously by her employer and that she was not being listened to. As a result she felt very anxious about raising her growing concerns with her manager. Alexa came across GCA while searching for support online, feeling that she and her partner were becoming “more and more lost” when it came to getting help with her caring role. She said “no one told us any information [relating to caring]. The GP told us nothing, the council told us nothing. Then I found GCA“

Alexa spoke with the support worker for the Working Carer service, sharing her issues regarding shift patterns. This led first to Alexa being made aware of her right to time off and dependents leave. She then began to work 1:1 with the support worker, on ways of making a formal request to her employer for an alternative working pattern. Alexa recalls,

“my support worker wrote two letters to my manager on my behalf, which helped very much. [My employers] agreed to me having more regular and condensed hours at work but I don’t think they would have taken my case seriously without Gateshead Carers [Association] on my side”

The change to Alexa’s working hours has meant that she is now able to continue working, whilst reducing the time spent away from the cared-for person. She also feels that simply having the opportunity to talk to someone who understood the challenges she faced, reduced her feelings of stress and anxiety.

These case studies highlight the vital role played by GCA in helping individuals to stay at work whilst simultaneously undertaking a caring role. Added benefits for individuals are suggested as being a reduction in stress and anxiety relating to their caring role and a big plus point has been the accessibility of the services.
3.5 Short break and activity groups

Through this project GCA has established a Short Breaks ‘Plus’ programme, which included a variety of Short Break Groups to help newly found carers focus on their own needs and work on developing personal skills and interests. The aim of these short breaks was to help carers manage some of the negative effects often inherent to their caring role (e.g. social isolation, depression and poor physical health).

By March 2014, in excess of 90 Short Break group activities had been funded as part of the Hidden Carers project.

GCA records show that 264 individual carers accessed short breaks, which far exceeds the original target of 100. Many carers have participated in more than one group.

The following table shows the recorded Short Break groups/activities run as part of the project:

<table>
<thead>
<tr>
<th>Group / Activity</th>
<th>Subscribed members*</th>
<th>Sessions run</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adult Carers Social Group</td>
<td>75</td>
<td>7</td>
</tr>
<tr>
<td>LGBT group</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>Carers Allotment group</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Men’s Group</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Chinese Carers Group</td>
<td>30</td>
<td>5</td>
</tr>
<tr>
<td>Polish Carers Group</td>
<td>16</td>
<td>8</td>
</tr>
<tr>
<td>Roma Carers Group</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Substance misuse carers – Creative Textiles group</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>BAME women’s swimming group</td>
<td>59</td>
<td>40</td>
</tr>
<tr>
<td>African Women’s group</td>
<td>11</td>
<td>9</td>
</tr>
<tr>
<td>Trip to Alnwick Gardens</td>
<td>64</td>
<td>1</td>
</tr>
</tbody>
</table>

*All members did not necessarily attend every session.

In addition, the following groups were also run:

- Parents groups; Women’s Yoga group (all carers)
- BAME women-only swim and yoga
- BAME men’s health walks and badminton.

Some of these sessions were delivered in partnership with Gateshead Council’s Health Trainer Team and the Women’s Participation Officer.

Examples of the group activities organised by GCA as part of the project include:

- Social group: trips to open air museum; a river cruise; a trip to York.
- Men’s group: Bowling; snooker; visits to local landmarks.
- LGBT group: Theatre trip; bowling; tours of local music centre.
• Parents group meet while the children have taken part in: ice skating; trips to stables; trips to a sports centre.

GCA were particularly interested in establishing whether attending these groups resulted in increased confidence and carers being more able to cope with their caring role. After attending group activities, carers were therefore asked to complete a short evaluation form (see Appendix H).

Some of the items required carers to rate whether they felt the activity had: increased their confidence; increased their sense of wellbeing; given them a break from caring responsibilities; left them feeling more refreshed and relaxed; and whether they learnt something from other carers to help them in their caring role. 23 of the carers completed one of these evaluations. The following chart is a representation of those responses:

Feedback from participants of the Short Break Plus activities clearly demonstrates benefits to those attending across the full range of measures, with the vast majority of respondents either agreeing or strongly agreeing that the activities had a positive impact.

There were also some really positive comments from carers that had taken part in the Short Break activities, including:

• “The group has saved me from being all alone in the world […] I now have a life.”
• “[I got] a feeling that I am not alone and that there’s someone who cares.”
• “It’s a nice break away from our caring roles. A day we wouldn’t get if it wasn’t for [Gateshead] Carers Association.”
• “It’s a way of letting off steam away from the cared for person.”
• “I’m on my own a lot so it is very helpful in meeting other people, I don’t feel so lonely.”
“The support I received from everyone at GCA is immeasurable.”
“GCA has helped me enormously and given me strength I didn’t think I had.”
“I now plan little adventures for [cared-for person] and myself, it’s given me so much food for thought, a new lease of life.”

In addition to the Short Breaks project, funding has also been used to provide carers with:

- Pamper sessions at hotel spa facilities.
- Pamper sessions (nail care and make-up) at GCA group sessions.
- Driving lessons (£250 each, buying 10 lessons).
- Gym membership for carers.
- Interpreters for the Polish carer sessions.
- Interpreters for the Roma carer sessions.
- The translation of Short Break group publicity materials into Bangla (Sylheti), Punjabi, Polish and Chinese) in order to better reach carers within those BAME communities.

The short break activities have been received incredibly well by carers with nearly three times the original target figure already reached and still a further six months of the project to run. Both the questionnaire and narrative demonstrate a positive impact on carers sense of wellbeing and inclusion.
4. Conclusions

The following conclusions can be drawn about the progress and success of the GCA hidden carers’ project. They will be discussed here in relation to those service outcome goals set by GCA at the beginning of the project.

**Goal 1:** Over 700 previously ‘hidden’ carers will have improved health and well-being as a result of the reduction of stress caused by their caring role and increased access to information, advice and guidance.

**Outcome:**

To date, the GCA project has succeeded in identifying, advising and supporting a total of 724 previously hidden and hard to reach carers.

Indeed, the feeling of those involved in delivering the “Working Carers” aspect of the project was that referrals for their services “dramatically exceeded expectations” and quickly became oversubscribed in the first 12-24 months. Carer referrals are currently held on a waiting list for an average of 2 weeks, before outreach support can be delivered, showing the potential not only for this project to be continued, but expanded.

As referenced earlier, the enormous success of initiatives such as the NE Working Carers Tool-Kit has led to GCAs efforts being recognised on a regional scale, promoting carer support services to a potential 100,000 working carers.

Carers interviewed as part of the evaluation study said that the support they received from the Working Carers project had positively impacted upon their health and wellbeing. More specifically, they described a reduction in stress and/or stressful situations as being a common outcome of the help they received.

“After the initial phone call and someone listening and understanding what my family were experiencing, I felt like a huge weight had been lifted- in fact I cried, with the sense of relief.” [Catherine]

This qualitative data is positive. Responses by carers using the GCAs outcome measure show an average increase in reported feelings of health and wellbeing of 23% (see page 14).

Having the right information and support accessible by phone, email, drop-in group or online appears to have enabled a large number of carers to access services while balancing work commitments, family life or caring from a distance. Equally, setting-up a Polish language email service, linked to a social media and networking page for Polish
carers demonstrates GCAs creativity in catering for the needs of local carers (given that Polish and Eastern Europeans represent the biggest ethnic minority group in Gateshead – 2011 Census, ONS).

- The GCA project has succeeded in identifying, advising and supporting a total of 724 previously hidden and hard to reach carers.

- Carers interviewed as part of the evaluation study said that the support they received from the Working Carers project had positively impacted upon their health and wellbeing.

- GCA have been very successful in reaching almost triple the BAME community (11%) as a percentage of the overall Gateshead population (2011 Census estimated BAME community in Gateshead at 3.7%).

- Data from the project suggests a very positive change across all 5 aspects of the lives of carers based on the outcome measures used.

**Goal 2:** A minimum of 18 Gateshead based employers will have a better understanding of the problems and stresses faced by carers which will lead to the adoption of carer friendly employment policies for over 6000 employees (600 carers based on 2001 census) by the end of the project.

**Outcome:**

The GCA Hidden Carers project has both met and exceeded its goals in this area.

This is a considerable achievement and (as with the aforementioned 1:1 services), GCA staff involved with this aspect of the project believe that their success has only been limited by the capacity to meet demand.

GCA have continued to steadily increase the number of employers on their Charter of Carer Friendly Employers, an idea that appears to have proved very popular with organisations (see page 16). The development of this initiative into a regional charter appears to be a realistic next step with excellent potential for furthering the project.

GCA have also expressed an intention to extend the service to working with healthcare organisations such as GP practices. This would be a positive move given a recent finding that, whilst carers tend to find GPs helpful, the latter can be poor at referring carers to appropriate agencies or services (Audit Commission, 2004).

In their experience of providing 1:1 services to working-carers, the GCA support worker found that they had “often already dropped out of work before they seek help from GCA, as they were unaware of the support available”. This finding underlines the need for the work that GCA is carrying out through the Hidden Carers project: supporting both the employer and employee, to keep carers in the workplace wherever feasible.
The GCA Hidden Carers project has both met and exceeded its goals in this area. They have directly engaged with 18 employers in Gateshead, encouraging carer friendly employment policies and giving access to GCA services to over 25,000 employees (approximately 2500 carers, based on 2011 census estimates).

When employers were asked to rate their satisfaction with the input/services they had received, on a 10 point scale (where 1=’not at all’ and 10=’totally satisfied’), GCA received an average score of 9.4.

100% of the employers said that they would be “extremely likely” to recommend Gateshead Carers services to employees or other organisations if they need advice or help.

The successful engagement and work with local employers has led to further initiatives that have brought added value to the project, such as the NE Working Carers Tool-Kit, which has led to GCAs efforts being recognised on a regional scale, promoting carer support services to a potential 100,000 working carers.

**Goal 3:** A minimum of 100 carers will have short breaks from their caring responsibilities, resulting in increased confidence and carers being more able to cope with their caring role by the end of the project.

**Outcome:**

GCA have vastly exceeded this target with 264 individual carers accessing short breaks to date.

The importance of GCAs efforts in this area are reinforced by current research that found carers not receiving respite were far more likely to suffer from mental health problems: 36% compared to 17% of those carers getting time off from caring (Hirst, 2004)

- 87% of carers’ responses on GCAs Short Break evaluation forms showed that they either “agree” or “strongly agree” that being a member of one of the groups has given them increased confidence.

- In every case the majority of respondents also either “agree” or “strongly agree” that the short break sessions:
  - leave them less stressed and increased their sense of wellbeing
  - provided a good break from caring responsibilities
  - left them feeling more refreshed and relaxed
  - allowed them to learn something from other carers to help them in their caring role

- The short break activities have been received incredibly well by carers with nearly three times (264) the original target figure already reached and still a further six months of the project to run.
The narrative feedback in particular highlighted the value of these groups in combating isolation with a number of carers citing the value of being with other people.

GCAs work to promote awareness of the problems and stresses faced by carers in the workplace is further reflected in the fact that GCA has been selected as Charity of the Year 2014 by Sainsbury’s. Such recognition is important for the continuation and expansion of projects such as this one, with the charity relying on donations and funding to support free services to carers. GCA will use this opportunity to raise awareness of unpaid carers and to promote the hidden carers support service across the region.

It is clear that GCA have not only met, but exceeded, their intended outcomes. Feedback from both employers and the carers themselves demonstrates the high value placed on this service by those using it. Similarly both employers and carers would highly recommend this service to their peers.

It is estimated that by 2017, the population of the UK will reach a tipping point for care, where the number of older people needing care will outstrip the number of working age family members currently available to meet demand.

It is vital that this project continues to provide carers with the support they need to sustain their caring role, without impacting negatively upon their work, health and wellbeing: the kind of information, advice, and support provided by GCA will continue to be invaluable.
5. Areas for future consideration

1) The vast majority of the employers that GCA works with are very large public sector, or national private sector organisations. This has given them access to a huge body of staff and therefore potential hidden carers. In light of this success, GCA may wish to consider how they could build on this experience to develop their links with smaller businesses, which may be less likely to have existing carer friendly employment policies and HR support.

2) An option to extend the reach of the project would be to develop a programme of outreach ‘drop-ins’ at public locations aimed at identifying working carers. This would enable both employers and employees to access information about supporting working carers. An example of this might be an open stand at a local shopping centre.

3) Following the positive feedback from carers and employers about GCA’s services in the workplace, GCA may wish to consider monitoring any change in the number of carers they encounter, who have dropped-out of work before they seek help. A future decrease in this number, (i.e. more carers seeking support before caring impacts upon their ability remain at work), may be another good indicator of a raised awareness of GCA’s services in the workplace.

4) Given the success of the project in identifying and reaching carers from BAME communities, GCA should consider developing further specialist carer support for this group.

5) Due to the success of the Carers Charter, GCA should consider developing the role of Carer Champions within workplaces, to further support the roll-out of the Charter and provide consistency of support throughout organisations.

6) Data from the project suggests it could be beneficial to provide some focus to identifying, engaging and supporting male working carers.

7) GCA have introduced an innovative outcome measurement tool. The more data that they can generate and record, the easier it will be for them to establish the impact that their services are having. In moving the project forward, GCA may want to consider how they can increase the completion rates of the outcome-measures tool, enabling future practice and developments of the project to be more evidence based.

8) It has been clearly identified that the services provided by GCA as part of this project have been of great benefit to carers and employers within the Gateshead area. GCA therefore need to identify potential funding/resource opportunities in order to maintain and build on the success of this project, to continue identifying and supporting previously “hidden” carers.
Bibliography:

Age UK (2012) Care crisis wipes over £5.3 billion from the economy (www.ageuk.org.uk/latest-news/archive) [10th March, 2014].


Carers UK (2012) on behalf of 8 Charities supporting Carers Week 2012: In sickness and in health; a survey of 3400 UK carers about their health and well-being. (http://www.mssociety.org.uk/sites/default/files/In%20Sickness%20and%20in%20Health.pdf [18th June 2012]


Appendices:

A. Carers’ needs and service outcome questionnaire

Appendix A - Carer Star.pdf

B. Employers Guide to Working Carers

Appendix B - NE_WorkingCarers_.pdf

C. Working Carers Guide

Appendix C - NE_WorkingCarers_.pdf

D. Information Leaflet

Appendix D - NE_WorkingCarers_.pdf

E. Display Posters

Appendix E - NE_WorkingCarers_.pdf

F. Carer Friendly Employer Award

Appendix F - NE_WorkingCarers_.pdf
G. Carer Friendly Employer Charter

[PDF]
Appendix G - New_Charter-1.pdf

H. Short Break evaluation form

[Word]
Appendix H - GCA- Short break feedback