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1. INTRODUCTION

The Carer Survey 2012-13 in North Somerset is run by North Somerset Council (NSC) and is part of a national survey organised by the Health and Social Care Information Centre (HSCIC). The first survey took place in 2009-10 and provided many insights into the identity, experience and expectations of Carers in England. From 2012-13 onwards it will form part of the mandatory Adult Social Care returns. It will also be used to calculate the Adult Social Care Outcomes Framework measures relating to Carers.
2. EVALUATION

The Carer Survey in North Somerset was conducted in line with the guidance issued by HSCIC. Anonymised data was returned by North Somerset Council to the HSCIC on time for inclusion in the national data collection. Generally, the survey was successful and provides much valuable information to be used in developing services to Carers.

Two discussion groups were held in July 2013 with survey participants to discuss the data from the survey in order to add some qualitative data to support the survey analysis. We would like to thank the Carers who took part for giving us their time to attend these groups and to share their experience.

Sampling
The population targeted by the survey was people looking after a friend or family member who needed assistance due to disability, illness or ageing who had had an assessment from social services or its partner agencies within the previous year.

Response rate
The return rate to the Carer Survey was much lower than expected, reaching 51% overall rather than the anticipated 70%. This resulted in a higher confidence interval than requested by the HSCIC (±5.92% rather than ±5%). Thus the data is slightly, but not significantly less reliable than was originally hoped.

The return rate was estimated using the return from the voluntary Carer Survey in 2009-10 which we conducted in a single mailing and a slightly different sample of Carers. Additionally, social factors such as the the comparatively smaller range of Carers' services encouraged Carers to respond in 2009-10.

Publication and Use of Results
The data from the survey has been analysed by the research team at the council and the intial data reports and ASCOF Outcome measures are available via eConsult on the North Somerset Council website.

The report will be published in time for the results to influence tendering process for Carer support services which will start in April 2014. Therefore the issues identified and recommendations made as a result of the Carer Survey will be addressed in the new service.

Bias
This report is written with the intention of informing the development of services to Carers in North Somerset. Therefore more attention is directed towards areas of under-performance than would be the case if the report were an evaluation of Carer Services.
As the sample consisted of Carers known to statutory agencies it is not representative of all Carers in North Somerset. The Carers in the sample typically are long term Carers providing a great deal of support to friends or family members.
3. PROFILE AND IDENTITY OF CARERS

Carers who participated in the Carer Survey are generally women aged in their 50s and 60s caring for someone with mental health needs. The people for whom they care are either partners or elderly parents. Male Carers tend to be slightly older, usually aged between 65 and 75. This group is representative of the Carers known to social services or partner agencies. However, the 2011 Census shows that Carers amongst the North Somerset Population are slightly younger, aged between 50 and 65.

Most Carers known to social services spend long hours caring with many Carers answering that they spent either over 100 hours caring or answering that they provide care ‘24/7’.

Carers often don’t identify themselves as Carers for many reasons. Sometimes they don’t recognise the title of ‘Carer’ and believe it refers to a paid care worker or other formal role. Very often they assume their caring role very gradually so that their expectations change, thus the Carer is unaware of the responsibilities they are undertaking and the impact on their own life.
4. SERVICE PROVISION

Overall, Carers are satisfied with services provided to service users and Carers. 139 (79%) of Carers answered that they were satisfied with support or services within the last 12 months. Respondents said that the person they care for mostly used equipment, home care and respite care, whilst the Carers mostly use information services and Carer support groups.

A further 61 respondents said they had not received any services within the last 12 months; further investigation showed that they generally did not recognise services provided by partner agencies or that the Carer misunderstood the question thinking it only applied to services provided directly by social services.

Several Carers commented that they did not use services such as advocacy or the Carer’s Emergency Response Scheme as they did not know these were available to them. There is a need to improve awareness of the support available. Additionally, when contact with statutory services came to an end, usually because support services had by then been set up for the cared-for person, some Carers felt abandoned as they did not feel clearly informed that contact with statutory services would cease at that point. They did not understand how to access support if services were failing or their needs changed. Carers expressed that they were part of a system for the cared-for person they did not understand how to use, for example, they did not understand that community mental health services will cease when the service user moves into a permanent residential or nursing placement.

Carers of adult children with disabilities said they felt there is a ‘gap’ in services when transferring from children’s to adult services. This is in reference to the type and volume of service provision.

Some Carers find support in their religious communities. There is opportunity here for early identification and preventative work. These groups may prefer to remain autonomous but social services may be able to offer resources to enable religious communities to support Carers, such as information and advice.
5. CARER INVOLVEMENT

Carers were asked how involved they felt they had been in discussions about the person they look after. Half the people who answered this question said they always or usually felt consulted. The remaining half either said that they were only sometimes or never consulted, or that there had been no discussions they were aware of. This is highly relevant as everyone in the sample frame had some involvement with social services or partner agencies such as Avon & Wiltshire Mental Health Partnership within the year prior to the survey.

Some respondents noted that they had been involved at certain times or with certain organisations, but at other times they were not involved.

Carers felt that barriers to their involvement were:

1. the apparent lack of co-ordination between health services and social care services;
2. the lack of explanation of how social care systems work;
3. and what to do when services fail or their needs change.

They felt that this could be overcome by better communication between the Carer, the person the Carer looks after and the organisations involved:

1. Professionals should explain who they are, and what agency had referred the Carer or service user.
2. Professionals should explain the social care process and what the Carer should expect from their organisation
3. Articles in council publications such as NS Life and the North Somerset Council could provide information.

Some Carers suggested they would find it helpful to have a list of ‘freebies’ they could access as Carers, and having a list of useful contact telephone numbers and websites.
6. ACCESS TO INFORMATION

Information about caring, about Carer services and about services to support the cared-for person was a repeating issue in the data from the Carer Survey.

Question 13 asked how easily Carers were able to find information and question 14 asked how helpful that information had been. Of the respondents who had answered each question, 119 respondents (52%) answered that they found it very easy or fairly easy to find information and 102 respondents (69%) said that the information had been helpful.

61 respondents (26%) said they had not looked for information and 57 respondents (25%) said they had not been given any information. Further exploration revealed that in many cases Carers don’t realise, especially in the early months of caring that they need help as changes happen gradually and therefore the Carer becomes accustomed to a new ‘normality’ and their expectations change. In some cases Carers feel that it is their responsibility to look after the person they care for and feel they have failed if they have to ask for support. Another recurring issue was that Carers are unaware that there are services to support them in their caring role.

When Carers seek information it is most frequently to find out about services to support the person they care for, to get advice on how to care for the person they look after, or to find out about benefits or financial matters. Carers most frequently use internet search engines or contact social services to find this information. They found information online, from social services, Crossroads and Alzheimer’s Society. The greatest number stated that they did not find the information they were looking for, although it should be noted that in some cases they are seeking a resolution that is not possible.

In group meetings, Carers recommended that information is provided via the GP practices as that is the logical place for them to look. However, Carers do not want a large display of leaflets as it is too public a display to pick from so “everyone would know what is going on in your life”. They suggested the Crossroads newsletter as it provided much good information, particularly on financial matters.

Carers also suggested that we make better use of North Somerset Council’s Life magazine as it is distributed to all addresses in the area.

Online information is useful to Carers as it is often difficult for them to leave the house. Carers found that information was not easily available on the North Somerset Council website and that information contained a lot of jargon and acronyms that were difficult to understand. Carers noted that not everyone can use the internet, either because of lack of access or simply not knowing how to use a computer. This is particularly applies to older Carers.
Carers raised the issue of disseminating information in rural areas. Most resources are in the larger towns in North Somerset and therefore Carers, particularly those without internet access, living in rural areas find it difficult to access information. Carers suggested making better use of parish councils and religious communities.

Carers Assessments were identified as an excellent method of providing information relevant to the Carer and good ‘signposting’ at the right time. Carers said they liked having a person to talk to.

Carers felt there was a need for clear information and advice on financial matters such as Power of Attorney (PoA) and managing finances for someone who lacks mental capacity.
7. EMPLOYMENT

As well as the financial element of employment Carers felt that paid and voluntary work were valuable in giving them a much-needed break from their caring role, and a life outside caring. Carers felt that large organisations were better able to support them maintain their employment and their Caring role. Evidence from Carers indicated that smaller organisations appeared less willing or less able to support Carers.
8. ACTION TAKEN SINCE PREVIOUS SURVEY

Publicity for Carers’ support via the council has generally focused on ‘do you look after someone?’ rather than using the term ‘Carer’ as Carers often do not see themselves as such.

Articles have appeared in North Somerset Life magazine to promote services which support Carers.

A pathway has been established so that Avon and Wiltshire Mental Health Partnership identify Carers when someone is diagnosed with dementia. The person with dementia and their Carer is provided with a copy of the North Somerset Dementia Information Pack which outlines support available. The Carer is then referred to Alzheimer’s Society for support unless they opt out of this. This provides early identification of Carers and the provision of information and advice to enable them to avoid crisis.

Crossroads Care North Somerset have extended their in-reach into GP surgeries in the area to provide information, advice and support to Carers via their GP surgery. They have placed Carer Information Packs in each surgery.

The Time for Me training course has been set up by North Somerset Council’s Community Learning team to provide Carers with information on the caring role, their legal rights, the support available, and ways to take care of themselves. In response to Carer feedback in the last survey replacement care is available free of charge for the cared-for person to enable the Carer to attend the course.

Increased number of Carers now access Carers Assessments and Carers Direct Payments.
9. NEW CARER CONTRACT
North Somerset Council is currently in the process of tendering for a new Carer support services contract which is joint-funded with NHS North Somerset Clinical Commissioning Group. The service is due to commence in April 2014. It is aimed at both young Carers under 18, and adult Carers. The information gained from this survey plays a fundamental part in shaping the service specification against which bidders will be required to design their model of service so that it is responsive to the needs of local Carers.
10. RECOMMENDATIONS

1. Information on NSC and partner websites needs to be improved with better access and links to other organisations.

2. Pro-active work is needed to identify and provide information to Carers on employment before they reach the stage of reducing their hours or giving up work. Work is also needed to inform employers of their obligations to Carers, and of the advantages to their business of supporting staff who are Carers.

3. Improvements to involving Carers in discussion about person they care for:
   - Professionals to explain their role and organisation.
   - Clear communication from professionals about what Carers can expect from them, about what help is available, and clear written records.
   - Carers to be informed of how the care system works (Eg. that once services are finished the referral closes and they must contact social services if their needs change.)
   - Clear explanation of how to contact social services should services fail or their needs change.

4. Improve early identification of Carers
   - Raise GP awareness of Carers’ issues and care support and their ability to signpost.
   - Help people self-identify as Carers
   - Provide information in a regular series of articles in Life magazine

5. Enable Carers to continue in their Caring role.
   - Distribute Crossroads newsletter in GP waiting rooms
   - Promote Carers Assessments as a means of accessing information, advice and support as required
   - Promote Carer Direct Payments
   - Provide information in a regular series of articles in Life magazine
   - Promote better information and advice. We need to help Carers realise what they need as they themselves adjust their expectations as their caring role develops.

6. North Somerset Council needs to work with local employers to ensure that staff with Caring responsibilities are valued members of staff and are supported to balance their employment with their Caring role.

7. Statutory and third sector services need to increase their focus on preventative work with Carers to avoid crisis.

8. An increase in the integration of local health and social care services will improve Carers’ experiences of services.

10. Staff in statutory services should provide Carers with information during their contact with Carers and should ensure when they end their involvement that Carers know who to contact for further information or advice in future.

11. Statutory and third sector services should ensure that their services are well-publicised to Carers.
11. OPPORTUNITIES FOR FURTHER RESEARCH

The Carer Survey asked people if they would be available to take part in further research. Therefore we now hold a list of people who may be able to participate in new research.

Employers

Some organisations are better able to support their employees. Anecdotal evidence suggests that larger organisations are more supportive than small organisations. Research could reveal whether this is the case generally and how to help organisations support Carers in their employ.
12. APPENDICES

Appendix 1: Guidance document from Health and Social Care Information Centre


Appendix 2: Glossary

<table>
<thead>
<tr>
<th>ASCOF</th>
<th>Adult Social Care Outcomes Framework (nationally agreed indicators of the efficacy of social care intervention).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer</td>
<td>Someone who provides regular unpaid assistance to someone who needs extra help due to illness, disability or old age.</td>
</tr>
<tr>
<td>HSCIC</td>
<td>Health and Social Care Information Centre (organisation running the national survey)</td>
</tr>
<tr>
<td>OT</td>
<td>Occupational Therapy or Occupational Therapist</td>
</tr>
</tbody>
</table>
### Appendix 3: Adult Social Care Outcomes Framework

<table>
<thead>
<tr>
<th>Outcome 1D: Carer Reported Quality of Life *</th>
<th>North Somerset</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>8.7</td>
<td>8.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 3B: Overall Satisfaction of Carers with Social Services</th>
<th>North Somerset</th>
<th>England</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>46.2%</td>
<td>42.7%</td>
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</table>

<table>
<thead>
<tr>
<th>Outcome 3C: The proportion of Carers who report that they have been included or consulted in discussions about the person they care for</th>
<th>North Somerset</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>70.0%</td>
<td>72.8%</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 3D: The proportion people who use services and Carers who find it easy to find information about services. **</th>
<th>North Somerset</th>
<th>England</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>70.0%</td>
<td>69.0%</td>
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</tbody>
</table>

* Maximum score is 12.

** Outcome 3D is joined to the equivalent question from the Adult Social Care Survey to produce the final outcome - therefore the score indicated above is NOT the final outcome and is only the Carers element of this indicator.