Joint strategic needs assessment - Carers (2016)

Topic information	
Topic title	Carers
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Executive summary

Introduction

The Care Act 2014 defines a carer as anyone who provides any amount of unpaid care. Carers are Nottingham City's largest form of 'early intervention', supporting the most vulnerable citizens and preventing the people they care for from requiring greater degrees of health and social care support. By supporting carers services are able to improve the carer's quality of life and support the cared-for citizens to remain in their own homes, maintain independence and reduce their incidences of requiring hospital admissions and residential care.

The greatest opportunities to improve carers' quality of life are through improving early identification, assessment and support, with recognition of the huge value that carers provide to health and social care. A key aspect of this is providing joined up support from Health and Social Care. Demand for health and social care support is expected to rise over the next 20 years, due to a range of factors including an ageing population, and an increase in the number of people living with a limiting life long illness or disability.

There are approximately 27,000 carers in Nottingham City (2011 Census data) approximately 3,300 of whom are under 25 years old. Carers often don't identify themselves as such, therefore the number of carers identified through the Census is likely to be a significant under-estimation. Around 1,140 Carers Assessments were carried out in 2015/16 which represents a small proportion of the carers in Nottingham City.

Local authorities have a duty under The Care Act 2014 to proactively identify, assess and look at how they can meet the needs of carers, including the carers of citizens who are not receiving social care support. The Care Act requires local authorities and Clinical Commissioning Groups (CCGs) to work to bring together Health and Social Care services to provide tailored support for citizens.

Irrespective of background, gender and age it is usually the condition of the cared-for person that has the most impact on the health and wellbeing of the carer. Conditions such as mental health problems, dementia, learning disabilities, physical and sensory impairments and

substance misuse contribute to increased use of health and social services, and increased social isolation for both the carer and the cared for citizen. Such circumstances also affect the quality of care given, due to the increased burden they place on the carer. High levels of stress and low levels of perceived wellbeing are common amongst carers.

Young carers (aged under 18) can experience difficulties in school, feelings of loneliness and isolation, and report feeling stigmatised by teachers and by their peers.

For further information on the groups more likely to need support from carers please refer to the relevant chapters including adults with learning disabilities, dementia and adult mental health.

Unmet need and gaps as identified in the 2016 Carers Strategic Commissioning Review

- A key issue for carers is that they often remain 'hidden' from services and support. Carers often don't recognise their own situation or that help is needed until they have been carers for a significant length of time and have usually had negative experiences as carers.

- Despite services being in place, carers tell services that they don't know where to go for information and support. There are overlaps and duplication across some of the support services, and limited links have been developed between the organisations commissioned to support carers, meaning it's not always clear where to go for support.

- Due to the pressures in social services there can be waiting times in Adult Social Care (ASC) of several months for non-urgent assessments. The Carers First service carries out Carers Assessments of behalf of Nottingham City Council. Whilst this was intended to alleviate pressure in ASC the numbers of carers having assessments through Carers First are much lower than anticipated.

- Carers identify that the need for respite is a high priority; however uptake of respite through the commissioned pre-eligibility pathway is low. Uptake of respite through ASC and the Dementia and End of Life (EoL) pathways indicate that there are issues with the operation of this pathway and that the balance of capacity in the respite services isn't correct.

- Engagement with carers and carer support services is variable across healthcare providers, GP practices, care providers and schools. These organisations have a key role to play in identifying, signposting and supporting carers. In consultations, carers stated they were particularly dissatisfied with the level of support provided to carers of citizens with mental health problems.

- Young carers are a particularly vulnerable group who can experience substantial physical, emotional or social problems, and encounter difficulties in school and elsewhere. Young carers have significantly lower educational attainment at GCSE level, and are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19 (Children's Society, 2013). Young carers often miss out on key aspects of childhood and development such as socializing with peers. Families where there is a young carer are often reluctant to seek support due to fear of perceived failure and intrusion/family

separation by services. Schools have a particular role in supporting carers aged less than 18 years; young carers report that support varies widely.

- Schools have a particular role in supporting carers aged less than 18 years; young carers report that support from schools varies widely, and that their requests for additional time and flexibility are often 'not taken seriously'.

- As they each maturity, young adult carers are known to disengage from young carers support, but not to engage with adult services. A number of flexible engagement options have been trialled in Nottingham and Nottinghamshire; no single model for supporting this cohort has been particularly successful.

- Carers identify that fears about what would happen to the cared-for person if they became unable to provide care have a significant impact on the carer's emotional health and wellbeing. However 83% of carers who care for a son or daughter living with them have not planned for when they are no longer able to deliver care, and 56% of carers aged over 70 whose son or daughter lives with them have not planned for when they are no longer able to care.

- In Adult Social Care, carers are regularly included in determining support for the cared-for citizen. However carers' involvement often ends after the cared-for citizen is referred to their care provider. Many care providers don't communicate with carers if the cared-for person has mental capacity and can make decisions about their own care and support. This can lead to misunderstandings about care, aspects of care not being carried out at all, and, in some cases, lack of support.

- Many carers of working age feel forced to give up work due to caring responsibilities, and many find it difficult to return. Carers often experience considerable financial hardship, a fifth of carers who reduce their working hours being £10-15k a year worse off and a further fifth losing around £15-20k annually. Many older working carers aged 55-64 years of age are likely to lose at least £30k a year.

- Due to the variations in data recording systems and associated practices across the huge number of organisations supporting cared-for citizens, it's not always currently possible to trace the carer through the records of the cared-for citizen, and link them together to co-ordinate support.

Recommendations for consideration as part of 2016 recommissioning

- Carers often remain 'hidden' from services and thus don't access the support they need. All professionals should attempt to recognise those with caring responsibilities and signpost them to appropriate support.

- Commission a true 'single point of contact' hub jointly between Health & Social Care, to improve awareness of support available, both to carers and the professionals who can help to identify them. A single point of contact would simplify the process by which professionals can refer, and therefore increase the likelihood that they would do so.

- Widespread outreach and promotion should be a core function of the service, to increase the understanding of what being a carer is as well as where to go for support. Included in the service model should be both capacity for and expectation of carrying out a significantly increased number of Carers' Assessments on behalf of the Local Authority.

- Continue to provide respite to citizens identified through social services as eligible, through Adult Residential Services. Provide a free inclusive respite service, for carers who are not in receipt of ASC respite and meet specified criteria. This service should provide fixed-term support (with the exception of citizens accessing End of Life pathways) whilst care packages or other support is put in place, and should not attempt to replace care packages.

- Training and support is needed to improve how agencies such as healthcare providers, GP practices, care providers and schools identify, support and work with carers. Consider developing CQUIN measures for services that support the cared-for person to encourage these services to offer advice, training, etc. to carers as part of the support for the person that they are caring for. Work with providers to develop the market in respite/short break options for citizens with LD and mental health problems.

- Retain a separate Young Carer support service, which specialises in understanding and supporting the needs of young carers, and which must also have strong links to the Carers Hub. Young carers report that they would not be comfortable seeking support alongside adult carers, and would be unlikely to attend groups or share their feelings with an adult cohort. The young carers' service must include social activities to give young carers opportunities to enjoy themselves with peers, and time away from caring responsibilities.

- Continue to include the requirement for outreach work in schools in the Young Carers' service. Utilise our influence in education to improve support for young carers' through schools.

- In the Carers Hub and the Young Carers service commissioning, include the requirement for the services to work together to develop a pathway for supporting young adult carers, which is flexible and meets the needs of the individual.

- Require that the new Carers' Hub works with carers to develop support plan and Carers ID cards for carers of all ages. ID cards would identify the carer as such, serving a dual function of recording the carer's designation as such, for use when interfacing with services, and in the event of an emergency, alerting the finder to the presence of a person with support needs, and who is not now being looked after. The finder could then contact the emergency contact listed on the card, and the Hub to aid enacting the emergency plan. This would provide re-assurance for both the carer and the cared-for citizen.

Further recommendations

- Utilise all of the resources within our communities and not just rely on specifically commissioned services to support carers. The greatest improvements for carers will be made by improving engagement of organisations that support the cared-for citizen (Primary care, care agencies, community healthcare teams, pharmacies etc.). Look at opportunities to include the requirement to work with carers in all relevant contracts.

- Improve systems for recording data across health and social care, linking the carer and the cared-for citizen to improve reporting of issues affecting carers at individual and population level, and assist in organisations in providing co-ordinated support.

- Consider how other departments/organisations can help to reduce financial impact of caring, for example through discounted wellbeing services, reduced cost transport, hospital parking and free/low cost activities.

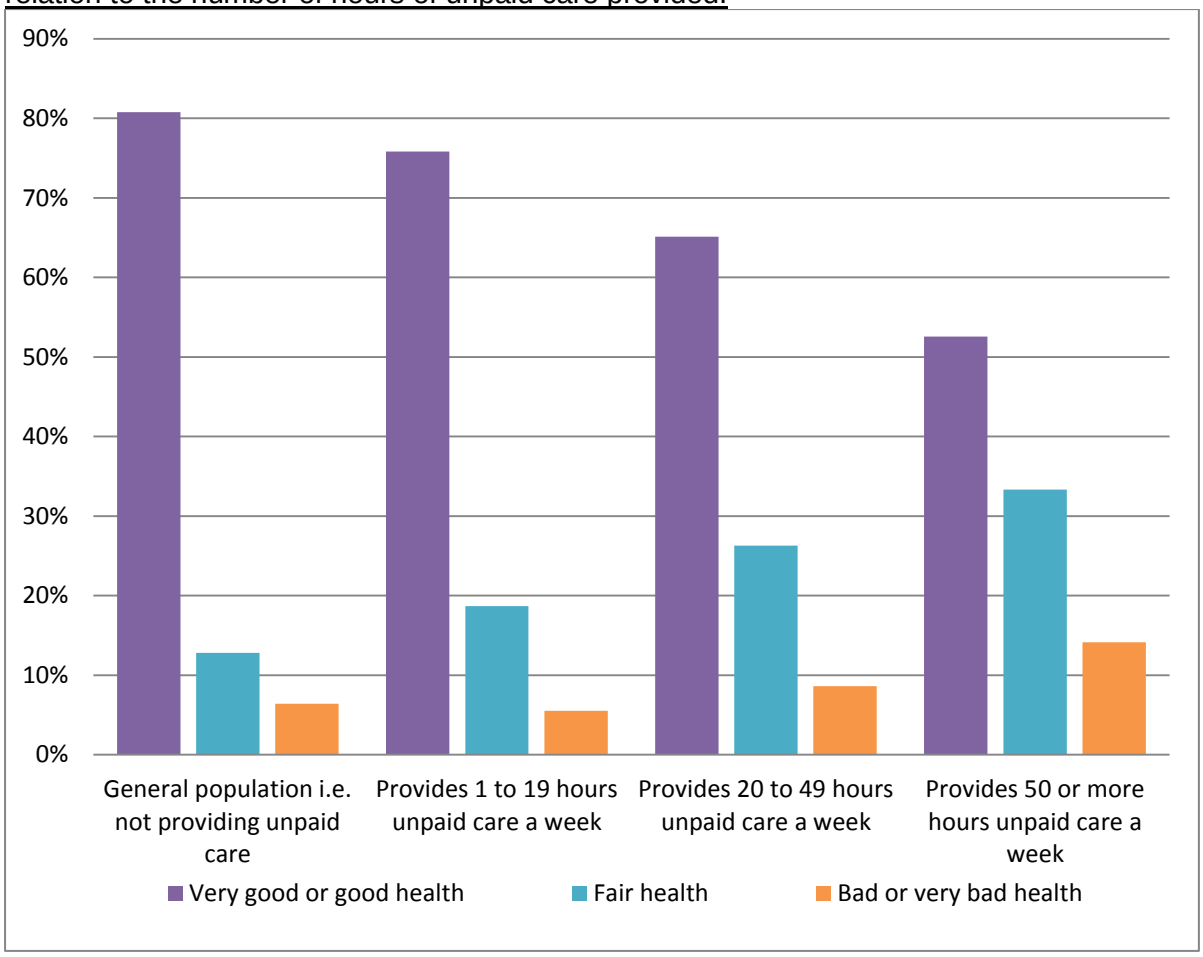
1) Who is at risk and why?

The 2011 Census identified that 5.4 million people in England were providing unpaid care, with over a third of all carers providing 20 or more hours of care a week. As many carers don't self-identify the true figure is likely to be much higher.

Carers account for around one in ten of the population, and are more likely to be female than male with an approximate 1.3 female carers for every male carer. The reported figures are approximately the same proportion of the population as those in the previous Census (2001), however there has been an overall increase of 5% on 2001 figures.

It is clear from the 2011 Census that the general health of carers deteriorates incrementally with the increasing hours of care provided. 5.2% of carers reported their own health as 'not good' and this rose to almost 16% among those caring for more than 50 hours a week – see fig 1. below.

Fig 1. Carers's self-reported perception of health (as a % of the total in each category) in relation to the number of hours of unpaid care provided.



While 55% of female adult carers and 44.9% of male adult carers reported they were economically active, only 12.1% of women and 9.3% of men were working full-time

alongside caring responsibilities and only 1.2% of women and 1% of men reported they were in full-time employment while providing 50 hours or more care a week.

Irrespective of background, gender and age it is usually the condition of the cared-for person that most impacts on the health and wellbeing of the carer. Conditions such as mental health problems, dementia, learning disabilities, physical and sensory impairments and substance misuse contribute to increased use of health and social services and increased social isolation for both the carer and the cared for. Such circumstances also affect the quality of care given, due to the increased burden they place on the carer.

Carers UK's *The State of Caring* annual surveys and the *Caring & Family Finances Inquiry* (Feb 2014) evidenced that many carers of working age feel forced to give up work to care and after a period of absence many find it difficult to return to the labour market. The State of Caring survey in 2011 found that of carers who had given up work or reduced their working hours to care, a fifth were £10-15k a year worse off and a further fifth were losing £15-20k annually. Many older working carers aged 55-64 years of age were likely to lose at least £30k a year.

The highest level of carers' needs were reported among carers:

- With mental health problems of their own
- Carers from Asian/British Asian Communities
- Under the age of 64
- And among those caring for periods of 15 -20 years.

The vast majority of carers in this country are not in touch with social care.

Different groups of carers can have different experiences and needs. Young carers can experience substantial physical, emotional or social problems, and encounter difficulties in school and elsewhere (SCIE, 2005). The amount and type of care that young carers provide can vary greatly, and does not predict how far the health or well-being of each young carer may be affected.

In addition, young carers have significantly lower educational attainment at GCSE level, and are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19 (Children's Society, 2013).

Carers of people with people with learning difficulties are often parents or other relatives of a learning-disabled individual, who may now be an adult. These carers often face a life-long caring role as the life expectancy of people with learning disabilities has increased significantly, and more people with learning disabilities are now expected to outlive their parents.

As the person with learning difficulties ages, their needs, and the needs of their elderly parent, may lead to mutual caring situations. Often in such families the carer and the person with learning difficulties only come to the attention of Adult Social Care when a crisis occurs, for example, when the carer or adult person with learning disabilities becomes ill, or physically incapacitated, or is suffering from dementia. In order to offer support, it's important to identify this hidden population of carers before a crisis occurs.

Mencap's report 'Housing for People with a Learning Disability' states 83% of carers whose son or daughter lives with them have not planned for when they are no longer able to deliver care. The report goes on to state that even older carers are not planning for the future, with

56% of carers aged over 70 whose son or daughter lives with them having not planned for when they are no longer able to care.

Nationally, approximately 13% of carers care for someone with a mental health condition. Such carers can be reluctant to discuss their role due to the stigma still attached to mental health. Mental health conditions can fluctuate, are often misunderstood, and can cause considerable emotional distress to carers. The issues of confidentiality and information-sharing between mental health professionals and carers are difficult and complex to resolve as healthcare staff have a duty to both patients and carers not to disclose confidential information.

Those caring for someone with dementia comprise 11% of all the carers in the UK. Dementia is one of the main causes of disability in later life and the number of people with dementia is rising yearly as the population ages. Dementia can affect people of any age but is most common in older people, particularly those aged over 65 years.

Dementia places a particular burden on carers and family members. Timely diagnosis and intervention is helpful, as it enables the person with dementia and their carer/s to come to terms with the disease and make plans for the future. Many of those with severe dementia, especially those over 85 years, have a combination of mental and physical problems. Many of the carers of older people with dementia are themselves elderly up to 60 per cent of whom are husbands, wives or partners.

Carers of people with dementia generally experience greater stress than carers of people with most other support needs with nearly half having some kind of mental health problem themselves. However carer support and education can enable more people to live at home for longer and prevent carer breakdown, which is a major cause of people needing to move into long-term care.

2% of the population experience addiction in family at some time with the rate in Nottingham similar to that in other cities. The contribution of families and their role in treatment/detox is recognised. Due to the stigma and shame surrounding drug or alcohol use, carers of people with substance misuse issues don't tend to engage with carer support services or carers assessments, only with substance misuse services.

There is concern that young carers of parent with substance misuse are remaining hidden due to fear of the involvement of outside agencies, not wishing to "betray" their parents, fear of losing their parents, whilst parents may have concerns about their children being taken into care.

2) Size of the issue locally

The 2011 Census suggests that there are approximately 27,000 people who provide unpaid care in Nottingham City, 8.8% of the total population. This is a slightly lower percentage than England (10.2%) and the East Midlands (10.8%). However, more adults in Nottingham aged 35 and older are providing provide more hours of care per week than the national average figures.

- 3.52% of the Nottingham population aged 35 to 49 years provide 50 or more hours of care compared to 2.68% nationally.
- 4.98% of the Nottingham population aged 50 to 64 years provide 50 or more hours of care compared to 3.66% nationally.
- 5.90% of the Nottingham population aged 65 years and over provide 50 or more hours of care compared to 5.29% nationally.

17% of Nottingham's carers are aged 65 and over, many of whom provide high levels of care. 45% of carers aged 65 years and older provide 50 hours or more per week.

7.98% of males and 10.40% of females in Nottingham provide some amount of care. Both sexes provide more care per week in Nottingham than the national average figures:

- 2.06% of men in Nottingham provide 50 or more hours of care compared to 1.96% in England
- 3.06% of women in Nottingham provide 50 or more hours of care compared to 2.84% in England

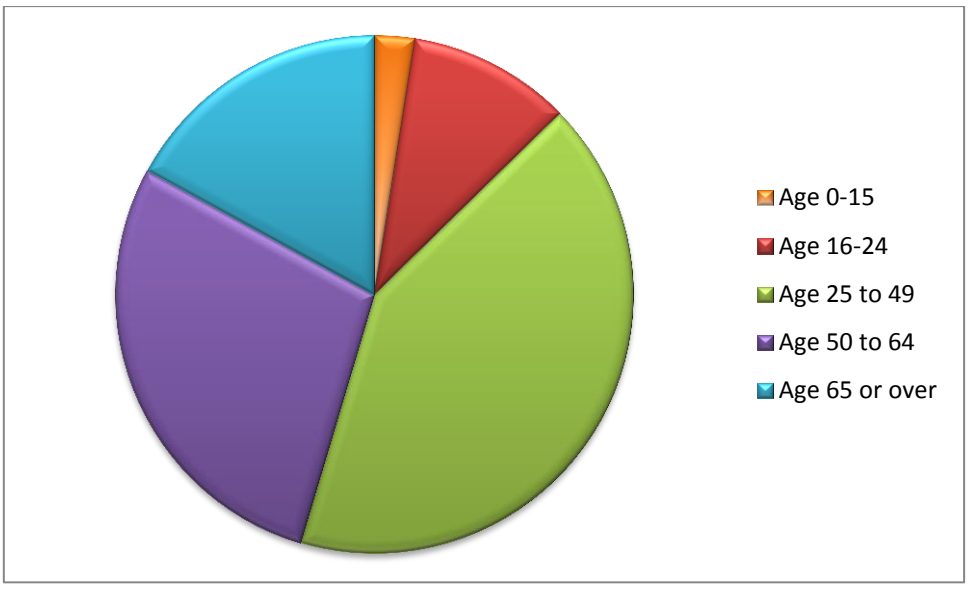
The proportion of women to men is approximately the same for Nottingham, East Midlands and England (1.3 female carers per male carer).

Carers often don't identify themselves as such, therefore the number of carers identified through the Census is likely to be a significant under-estimation. Around 1,140 Carers Assessments were carried out in 2015/16 which represents a small proportion of the carers identified in Nottingham City.

Overall this gives a picture of slightly fewer carers in Nottingham compared to the national average, but providing more hours of care per week.

Young Carers: The 2011 Census showed there are approximately 3,300 young people aged under 25 years old, who look after another person in Nottingham City. 2.5% of carers of whom are aged under 16 years old; a further 10% are aged 16-24 years (see fig. 2 below).

Fig. 2 Ages of carers in Nottingham as a percentage of the total number of carers in the city



20% of carers aged under 16 years provide over 20 hours of care per week. Many young carers are not currently being identified or assessed for support, and remain hidden from official sight for a number of reasons. These can include family loyalty, stigma, bullying, young carers' own lack of awareness of their entitlements, and reluctance to seek formal help.

Caring for someone with a learning disability: The 2011 Census suggests that there are approximately 6,000 citizens in Nottingham have learning difficulties. Only a sixth of these are known to Adult Social Care. 152 of the citizens with learning difficulties and known to ASC live with an older carer, all of these carers are aged above the average healthy life expectancy.

Caring for someone with a mental health problem: The Adult Psychiatric Morbidity Survey (McManus et al 2009) estimates that approximately 46,000 adults in Nottingham experience a common mental health problem in Nottingham such as depression, anxiety, phobias and obsessive compulsive disorder. It is unclear what proportion of these citizens has someone providing care for them.

Caring for someone with Dementia: The number of people aged over 65 living with dementia in Nottingham is predicted to rise from 2,914 in 2015 to 3,096 in 2021. This represents a 6% increase over 6 years.

Carers from BAME communities: The 2011 Census showed that the prevalence of carers amongst the BAME communities is approximately equivalent to that of the general population. However, higher than average incidences of providing unpaid care are reported amongst the Black Caribbean, Indian, Pakistani and Bangladeshi communities. 15% of Indian men and 19% of Pakistani women are carers, compared to the general population average of 11%.

It is likely that these figures represent only a fraction of carers in BAME communities. There may be familial expectations of caring in some cultures, where caring is seen as a normal function of the family, the carers may not self-identify and therefore do not receive any support, advice or carer's assessments.

Most ethnic groups in the city provide a similar amount of care to the average, with white British, Pakistani and black Caribbean groups providing slightly more, and mixed ethnic groups slightly less. Significantly more citizens from Pakistani and Bangladeshi communities provide greater amounts of care – over 2.3% of the Pakistani and Bangladeshi community provide 50 or more hours of care per week. Mixed ethnic groups tend to be younger and it is also known that likelihood of providing care increases with age.

A recent mapping undertaken of self-care support activities in Nottingham City highlighted the low number of services and groups that supported people from BAME communities who were affected by long term conditions. It is likely that a proportion of these patients have carers, and if the patient isn't accessing the right support this could potentially have a negative impact on the carer.

Parent/carers of disabled children: There are 7,700 children in Nottingham City with special educational needs and/or a disability (SEND). Many parent carers report struggling to access services for their child, lengthy processes and negative experiences, become disengaged from services so don't seek support for themselves, dependent on condition of child they may face a lifelong role.

3) Targets and performance

The Adult Social Care Outcomes Framework (ASCOF) 2015/16

<u>Domain One: Ensuring quality of life for people with care and support needs</u>

- 1D. Carer-reported quality of life.

- 1I. Proportion of people who use services and their carers, who reported that they had as much social contact as they would like. (See also PHOF 1.18)

Domain Three: Ensuring that people have a positive experience of care and support

- 3B. Overall satisfaction with social services of carers
- 3D. The proportion of people who use services and carers who find it easy to find information about support
- 3C. The proportion of carers who report that they have been included or consulted in discussions about the person they care for

The Public Health Outcomes Framework (PHOF) 2015/16

Domain One: Ensuring quality of life for people with care and support needs
1.18ii - The percentage of adult carers who have as much social contact at they would like according to the Personal Social Services Carers survey

Legislation, policies and strategy

National strategies

The Care Act 2014 places a duty on local authorities to proactively identify, assess and consider how they can meet the needs of carers in their area who might have support needs that are not being met. The Care Act defines a carer as anyone who provides any amount of unpaid care. The Care Act requires local authorities to identify carers' needs through statutory Carers Assessments. This duty extends to all carers, including the carers of citizens who are not receiving social care support.

Under the Care Act, carers are recognised in law in the same way as those for whom they care, regardless of whether that person has eligible care needs, or not. The Care Act defines a carer as anyone who provides any amount of unpaid care. From April 2015, councils have had a duty to carry out assessments for all carers who ask for one, and to pro-actively identify and offer assessments to carers.

Once the assessment is complete, the local authority must decide whether the carer's needs are 'eligible' for support from the local authority. This approach is similar to that used for adults with care and support needs. In the case of carers, eligibility depends on the carer's situation. The carer's needs can be met by providing care and support directly to the person that they care for, for example, by providing replacement care to allow the carer to take a break, as long as the person needing care agrees. In such cases, where the local authority charges for the type of care offered, the authority must carry out a financial assessment of the person who is cared for - the carer cannot be charged in such cases. An adult caring for a disabled child can get support through children's services.

Local authorities must also provide information and advice on local services to prevent carers' needs from developing further.

The Children and Families Act 2014 amended the Children Act to make it easier for young carers to get an assessment of their needs and to introduce 'whole family' approaches to assessment and support. Local authorities must offer an assessment where it appears that a child is involved in providing care. This legislation is aligned with similar provision in the Care Act 2014 requiring local authorities to consider the needs of young carers if, during the assessment of an adult with care needs, or of an adult carer, it appears that a child is providing, or intends to provide, care. In these circumstances the authority must consider whether the care being provided by the child is excessive or inappropriate; and how the child's caring responsibilities affects their wellbeing, education and development.

Local authorities have a clear duty to undertake an assessment of a young carer's needs for support on request or on the appearance of need. Local authorities are required to ensure that young carers are identified and to consider whether the young care is a 'child in need'.

The Government have indicated that the amendment to the Children Act works with provisions in the Care Act 2014 so as to apply equally to both children's and adult services. The Guidance for the Care Act reinforces this and stresses that young carers should not be left with inappropriate levels of caring responsibilities. The key difference in considering support for young carers compared to adults is that adult carers have a choice in their caring role that young carers lack.

The National Carers Strategy 2014-16 has key priorities to support carers to care effectively and safely; look after their own health and well-being; fulfil their education and employment potential; and have a life of their own alongside caring responsibilities.

By providing effective support for carers we will improve the carer's quality of life, reduce incidences of poor mental health and physical injuries amongst carers, and support carers to further their education, careers and other interests. This can help reduce carer breakdown and enable carers to continue to carry out their caring roles.

'No wrong doors: Working Together to Support Young Carers and their Families' is a local memorandum of understanding (based on a national template) between statutory Directors of Children's and Adult Social Services. It reflects the important new duties and powers placed on local authorities by the Care Act 2014, Children and Families Act 2014, and reinforced in the Young Carers Assessments Regulations 2015, the Guidance related to both of these Acts and "Working Together to Safeguard Children" (DfE – 2015). The memorandum promotes working together between Adult's and Children's social care services and Action for Young Carers.

Local strategies

Nottingham City's Joint Vulnerable Adults Plan (VAP) recognizes that there are large numbers of carers in Nottingham City, many of whom provide over 50 hours care per week. A key aim identified through the VAP is to improve carers' quality of life by ensuring the early identification and holistic assessment of their needs, and by supporting them to realise their potential so that they can have a life outside caring. By providing effective support to improve carers' wellbeing and avoiding carer breakdown, we will support vulnerable people and those with long-term conditions to continue to live as independently as possible in their own homes.

Nottingham City's Children and Young People Plan (CYPP) identifies young carers as a vulnerable group and includes a commitment to 'pay particular attention to helping them to achieve their potential'. This is also echoed in the Nottingham Plan. Children and young people will be supported to reduce the burden of excessive caring roles, to allow them to achieve their full potential, and to improve their own health and wellbeing outcomes.

This will be achieved by ensuring the early identification and holistic assessment of young carers' needs, and by supporting them to realise their potential so that they can have a life outside caring.

4) Current activity, service provision and assets

Carers in Nottingham may be identified and supported through a number of routes.

Adult Social Care
All citizens who contact Nottingham City Council for support from social services are referred through the Nottingham Health and Care Point (NHCP). A contact assessment is carried out to establish urgency, and as part of this contact assessment it is established whether there are any carers, and whether a carer is under 18 years old (a young carer). Urgent referrals are referred to the Rapid Response team and are dealt with within 48 hours – referrals involving young carers are always considered to be urgent. Non-urgent referrals are referred to the Community teams. If a Carers Assessments only is required (i.e. no assessment is to take place for the cared-for citizen), the referral is referred to Carers First, the carers' support hub for Nottingham City. In 2015/16 1,033 statutory Carers Assessments were carried out through Adult Social Care, most of these jointly with the cared-for citizen.

If a young carer is identified as a 'child in need', or there are safeguarding concerns, the young carer is also referred to Children's Services.

Primary care/healthcare
Where the cared-for citizen accesses health services and is accompanied by their carer, the carer may be identified and referred by the primary care/healthcare provider, into either NHCP or one of the support services below.

Additional support for carers
The following services are commissioned by Nottingham City Council and/or NHS Nottingham City CCG to support carers in Nottingham City -

- **The Primary Care Carers Support Service (PCCSS)** provides education and support for healthcare professionals in primary care and 1-1 case management support to carers of any age. The service will undertake carers' needs assessments to identify the most appropriate care package; which includes information/signposting, respite, health care and social care. However this is not a statutory Carers Assessments under the Care Act. The service provides dedicated support, information and awareness-raising of carers and how to identify them in the primary care setting. The majority of referrals to the service come from health care professionals and primary care. This is the only carer support services that receive multiple referrals from this sector. The service is extremely proactive in referring carers to other existing voluntary sector services e.g. The Carers Federation and to social care.

- **Carers First** provides a range of support for carers of a vulnerable adult or child in Nottingham City, including Carers Assessments for carers of citizens who are not receiving support from social services. This supports Nottingham City Council's legal obligations to carers. The current model provides a single point of referral (Hub), appropriate assessment and support options which may include training, advice, support groups or referrals to respite for the cared-for citizen, and signposting/referral to other support services as appropriate.

- **Carers Counselling Service** provides consistent, high-quality counselling to informal carers of any age, registered with a Nottingham City CCG GP practice, suffering from anxiety and non-delusional depression. Carers are offered a programme of individually tailored counselling, which can be telephone support and advice or face to face one to one sessions. The service provides consistent, high-quality counselling to informal carers of any age, suffering from anxiety and non-delusional depression.

- **The Community Rehabilitation Day Centre** facility offers support, training and social activities for people with learning disabilities and their carers. The service provides weekly 'drop in' activities for people with a diagnosed learning disability, such as arts and craft, dancing, cookery, games, films, sports and healthy lifestyle activities, and hosts a carer support/be-friending group for those carers of people with a learning disability.

- **Dementia Support Service** provides information, guidance and support to people with dementia and their carers. The service includes a programme of support and information aimed at the specific needs of carers of people with dementia, and a 'Dementia Café' which emphasises the importance of speaking openly about problems and promotes social inclusion for people with dementia and their families.

- **Action for Young Carers** provides support for carers aged under 18 years old. The service is highly innovative and is very well regarded by carers and professionals. The service has good links to both Adults and Children's Social Care – young carers are identified as a priority through the Rapid Response Pathway, and the service has an important role in identifying appropriate caring responsibility for young carers.

Carers Assessments

Carers Assessments are a statutory requirement under the Care Act. In 2015/16 1,033 statutory Carers Assessments were carried out through Adult Social Care, most of these jointly with the cared-for citizen. 104 Carers Assessments were provided through the Carers First contract (9%) – this is much lower than originally anticipated. Currently carers do not perceive that there a particular benefit to having a carers' assessment. (Carers UK data shows that nearly 60% of carers are turning down the offer of an assessment.)

Time pressures in ASC mean none-urgent cases waiting times several months. If Carers First were not offering statutory assessments, carers would either not have an assessment or wait for several months to receive them, increasing carer stress and risk of carer breakdown.
Therefore external commissioning of statutory assessments is preferable to offering statutory assessments through Adult Social Care only – however this is dependent on the provider's ability to deliver a significant number of statutory Carers Assessments to provide value for money.

Respite/short breaks
The need for carers to have breaks from caring roles is well established. In their report on the value of breaks for carers, Carers' Trust identified that carers experience a constant responsibility for the health and well-being of a vulnerable individual and that this creates strain on the relationship between the carer and the cared-for person.

> *'In order for time away from the caring arrangement to be effective for the carer, the carer needs to know that care is being provided in their absence to the same quality that they provide – otherwise their time away is affected by guilt, and their relationship with the person with care needs subject to strain. The need for a breaks service, in short, is the need for a service which provides an equivalent substitute to the care which the carer provides'.*
>
> (Carers' Trust 2013)

Respite/short breaks in Nottingham are available in the following ways:

Respite through Adult Social Care
Where the cared-for citizen (with the carer where appropriate) is assessed through Adult Social Care, and a care support package is agreed, this may include respite. Respite is provided to the cared-for citizen, so where the citizen pays towards the cost of their care they would pay towards respite. Respite can include sitting services with the cared-for person in their home whilst the carer has a break, taking the cared-for citizen out to engage in activities whilst the carer remains at home, day care such as access to day centres which support citizens with a range of needs, or residential care. There are day centres which support citizens with specific conditions, and citizens from specific communities such as the Indian, Pakistani, African or Caribbean communities.

Residential respite is available to support citizens with a range of needs. Nottingham City Council work with citizens to support them to remain as independent for as possible, so residential respite is usually for citizens with the highest levels of support needs when the carer needs a break. This is usually the highest cost support option, to both the local authority and to the cared-for citizen.

Older adults are by far the largest cohort accessing residential respite. There are many more care providers supporting this cohort than any other. The average number of days of respite accessed by citizens in this cohort is relatively high, and this category has the highest overall costs to the local authority. A small number of adults access specialist older adults' dementia/mental health support. The costs of this service are low, and the service appears to be good value.

A significant number of citizens access respite for learning disabilities. The number of citizens, number of days and cost per day are all relatively high, but the number of days accessed by each citizen are quite low. Very few citizens access respite due to mental health conditions, and there are very few providers of mental health respite. Citizens with mental health conditions access by far the greatest number of days of respite, indicating high need for respite.

Respite provided through carers' support services provide other options for access to respite services including:

- **The Carers' Respite service** provides respite support for carers, where the cared-for citizen is not eligible for support from social services. The service provides home-based respite for the cared-for citizen, where the carer requires a short-term intervention. (Where the cared-for citizen is eligible for support from social services, respite is accessed through that pathway). Referral to this service is through Carers First, and enables carers to plan regular breaks or respond to emergencies, and supports them to continue in their caring roles.

- **Carers Respite (End of Life and Dementia)**, provides respite support for carers of a patient who are 'end of life' or with a diagnosis of Dementia. The service provides respite to carers of patients deemed to be within the last 12 months of life in accordance with the Nottinghamshire End of Life Care Pathway (2009), and to carers of patients with a diagnosis of, or suspected, dementia. The service provides planned breaks and emergency support to meet unexpected or emergency needs of carers or to prevent a crisis occurring.

- **Carers BME Respite** provides respite for carers looking after older people from the African and African Caribbean community. This small service (supporting around 20-

25 citizens per year) provides personal care, domiciliary care, practical help/advice and signposting to other appropriate services as well as communication to prevent isolation. The service supports carers/patients in the community but also provides support to patients living at the housing association which is the partner organisation of Homecare Plus.

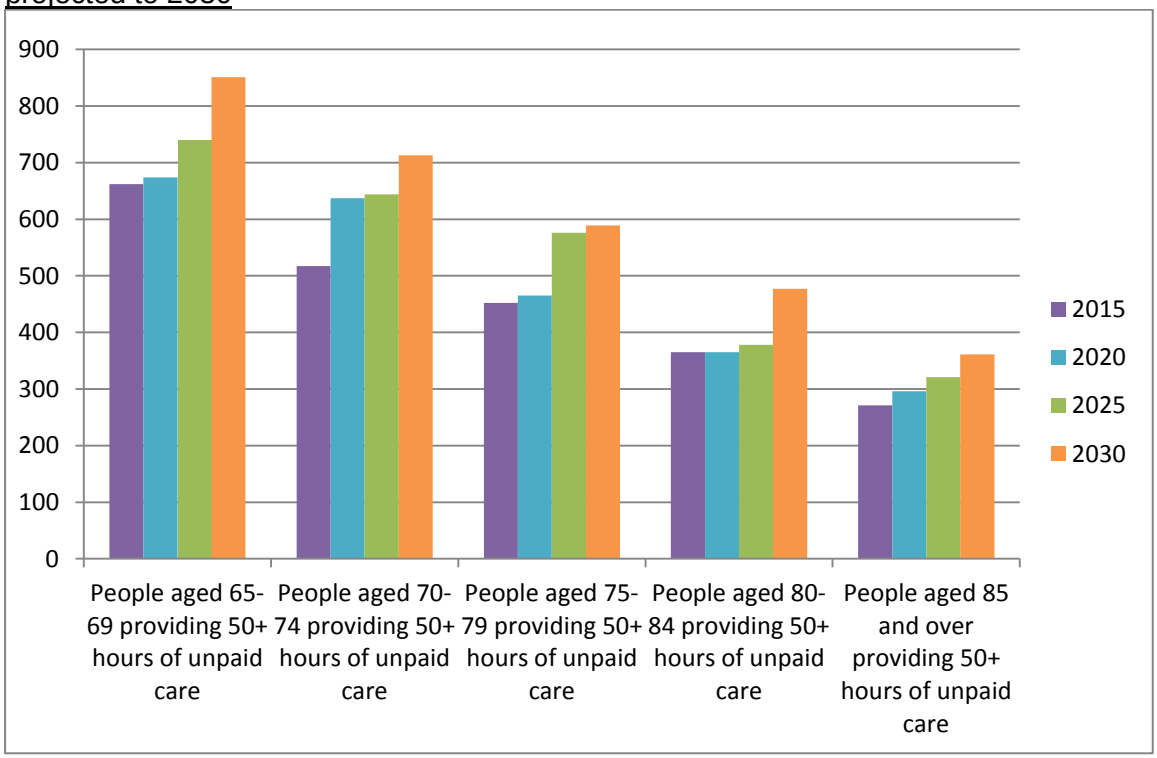
Key points about our current provision:

- The services are highly regarded, and have played an important role in providing support for the carers they worked with.
- A range of services exist to support carers in different settings. Carers First and the PCCSS both provide hub services however both services have strong links to differing statutory services.
- Links between the hub, young carers support and Adult Social Care teams are very strong with supporting carers is embedded in the systems to support the cared-for citizens.
- Action for Young Carers is highly proactive and have developed innovative support methods, for example development of a Young Carers app.
- Low numbers of statutory assessments are being carried out through the referral hub and the uptake of the pre-eligibility respite service is low.
- Many carers still report feeling unsure where to go for support.

5) What is on the horizon?

The number of people over 85 in the UK, the age group most likely to need care, is expected to increase by over 50% to 1.9m over the next decade, increasing the number of carers within society, but also increasing the number of older adults providing care (see fig. 3 below). Nationally, approximately 80% of people requiring long-term care receive care from their spouses, relatives and friends (Ferrer, 2015).

Fig. 3 No. of people aged 65 and over providing 50+ hours of unpaid care per week, by age, projected to 2030



In addition to the needs of the aging population, medical advances have improved the survival rates for long term conditions, babies born at very low birth weight and of those with life-threatening conditions such as cancer. Whilst this is a positive outcome, survivors can be left with physical and/or psychological complications for which they may require support. The rising numbers of citizens who require support to carry out essential tasks is expected to impact heavily on carers.

The number of Nottingham residents aged 65 plus providing unpaid care is projected to increase from 5,028 in 2015 to 6,626 by 2030, a 32% increase. Projections for different ages and the amount of care provided vary, the overall picture being more older carers (aged 65 and older) providing greater amounts of care. The number of Nottingham residents aged 65 plus who are unable to manage at least one domestic task on their own is projected to increase from 15,405 in 2015 to 20,155 by 2030, a 31% increase.

The number of Nottingham residents aged 65 plus who are unable to manage at least one self-care activity on their own is projected to increase from 12,667 in 2015 to 16,544 by 2030, a 30% increase. It's expected that there will be a significant overlap between these groups. The greatest increase in care needs is predicted in males aged 85 and over – a projected increase of 61% in the number of males aged 85 and over who are unable to manage at least one domestic task/self-care activity on their own. It is anticipated that in many cases, the additional support needs of these citizens will be met by unpaid carers.

The Nottingham City school population has risen by more than 3,000 (3,248) pupils since 2009, an increase of 8.45%. Numbers of children and young people with SEND continue to increase in line with the increase in the population, and the numbers of parent/carers increase with them.

6) What is working?

- Carers and Carers Assessments are strongly embedded Adult Social Care procedures for working with citizens who require support. Joint assessments with the carer and the cared-for citizen are standard, and where a carer contacts ASC for an assessment and no assessment for the citizen is required, ASC refer the carer to Carers First.

- Delegating the authority to carry out statutory Carers assessments is an innovative approach – several other local authorities are considering this approach, but few have delegated responsibility for formal carers assessments to an external provider at this time. The advantage of doing so is that it frees up capacity in Adult Social Care, enabling carers to be assessed expediently and avoiding long waiting times or the chance that carers may not seek assessment through the local authority at all – probably leading to worsening of circumstances and eventual crisis.

- The pathway supporting young carers through the Rapid Response team is very strong - social services have embedded identification of carers into their procedures for working with citizens who require support, and joint assessments with the young carer, their family and the cared-for citizen are standard.

- In recent consultations, support through Action for Young Carers was highly regarded by carers, and had played an important role in providing support to continue in their caring role. Action for Young Carers has been a highly proactive service, and has led developments such a young carers ID cards to aid recognition, a young carers' phone app to allow access to support at convenient times, with little commitment from the young carer if that is preferred.

- The work that the Primary Care Carers Support Service has done to improve the identification of carers within Primary Care is highly regarded and has provided essential support to carers - Primary Care is one of the most important and frequently used avenues by which carers come into contact with statutory NHS services.

- Key healthcare provider organisations such as Nottingham University Hospitals NHS Trust, Nottinghamshire Healthcare Trust and Nottingham Citycare Partnership have a Carers Policy or Carers Strategy in place to actively encourage staff on the wards to identify and support carers. NUH has also commissioned several pilots recently to support carers in secondary carer. Nottinghamshire Healthcare Trust has recently updated their strategy and their vision is to ensure that Carers, families and friends are valued, recognised and involved as equal partners in individual care and service planning.

  The Trust has also agreed to implement the Carers Trust Triangle of Care to ensure that we improve the partnership between service user, staff member and carer. In addition to the strategy the Trust has a dedicated carers support service to support the on-going development of support to carers within adult mental health services. The Adult Mental Health service has a long history of working with and providing support to carers, through individual work, support groups and educational forums.

- NHS Nottingham City CCG has encouraged commissioners to consider carers within all services and published the 'Think Carer Checklist' in 2014. The checklist included seven key points for commissioners such as having a set procedure for identifying carers, recognising carers as expert partners, involving carers in commissioning, including carers' measures in service specifications and evaluation of services, and the impact of the Care Act on commissioned services.

7) Local Views

A consultation on the direction of support for carers took place in January 2016. From this consultation carers identified the following key issues:

- Carers have asked us to maintain a register of all carers in Nottingham City who have had Carers Assessments (this information is in place), and for carers' I.D. cards for adult carers (they are already in place for under 18 year olds).

- Carers identify that improving support for the cared-for person is key to improving the life of the carer, and that Health and Social Care providers must include the carer in the development of the care package for the cared-for person, so that the care package becomes a holistic approach to care. Carers asked us to work with Health and Social Care providers to identify carers, signpost them to appropriate support and overcome barriers to working with carers, particularly around time and confidentiality.

- Carers have asked us to raise awareness with Health and Social Care providers of the need to work with carers and the importance of doing so; and to refer to all staff who provide paid care as care workers NOT carers in all communications with providers, and encourage providers to move towards this terminology.

- Carers did not feel that information on the support available for carers is widely known. Carers asked us to prioritise identification of carers so that support can be provided early, and to develop a single point of contact for carers, including advice,

information, emergency planning, Carers' Assessments, support, training, signposting to advocacy and other support, how to complain about services. Carers identified that there is particular confusion around boundaries between Nottingham City and Nottinghamshire County.

- Carers identify that improving access to respite provision is very important, and that carers are generally dissatisfied with the availability and choices of respite provision. Carers are concerned that poor rates of pay offered to care workers impacts on the quality of homecare and respite care. Health and Social Care providers contracted by Nottingham City Council and Nottingham City CCG should offer fair rates of pay to care workers (This is already in place).

- Carers have asked for support with planning for unexpected situations, to help carers to be more confident in their caring role knowing that contingency plans are in place should the worst happen. Carers asked us to work towards offering contingency planning at the point of the Carers' Assessments, and for Health and Social Care providers to include a record of any contingency plans within the cared-for person's care package.

- Carers acknowledged that their caring role often has a financial impact on them. Feedback about the one-off payment provided to carers in the County was very positive.

- Some carers are quite angry when the word 'carer' is also used to refer to care staff rather than carers, who provide unpaid support to family, neighbours, friends etc.

- In addition, Young carers' felt that they required -
    - Support from school/college
    - Access to appropriate support when needed
    - Time to themselves, and opportunities to engage in activities/hobbies.

- Young carers also highly value being taken seriously and the Young Carers I.D. card has been well received for this reason.

A small consultation was held in May 2012 with members of the Radford Care Group, an organisation that supports carers of people with Dementia to gather their views on the group and how it could be improved. Carers fed back that the group helped them as a carer by providing support; signposting to other services and information; enabling them to meet other carers. However they felt that the group could be improved by enabling some small group discussions and/or allowing some 1:1 time for questions so that the agenda of the group can be kept on track.

Key themes from other areas:

- The following key themes were found to be common to support for carers across other areas Single point of contact – inclusive Carers Hub model
- Jointly commissioned services with CCG/s
- Exploring options to deliver Carers Assessments through external organisations
- Less uptake of carers assessments than anticipated
- Smaller number of higher value contracts - streamlined referral pathway and economies of scale
- Online Carers Assessments as initial contact
- Working with BAME organisations to link with diverse communities
- Separate young carers' service

Examples of provision in other areas can be found in the appendix.

What does this tell us?

8) Unmet need and gaps as identified in the 2016 Carers Strategic Commissioning Review

- A key issue for carers is that they often remain 'hidden' from services and support. Carers often don't recognise their own situation or that help is needed until they have been carers for a significant length of time and have usually had negative experiences as carers. Widespread outreach and promotion is needed to increase the understanding of what being a carer is, and where to go for support. Carers that do not wish to access services and are coping and confident in their caring role should still have an awareness of support services and know where to go for support if their caring situation changes. This may apply particularly to some members of BAME communities, who may not wish to utilise services as they may prefer to draw on family support networks.

- Despite the presence of the Carers First hub, carers are still reporting that they don't know where to go for information and support. Carers reported that finding out where to go for information was difficult, especially as a new carer, and that there is a need for a single point of contact/information for carers. There are overlaps and duplication across some of the support services, and limited links have been developed between the organisations commissioned to support carers, meaning it's not always clear where to go for support. Limited links have been developed between the organisations commissioned to support carers. Carers' assessments undertaken by each commissioned service are slightly different, an there are overlaps and duplication between Carers First, Primary Care Carers Support Service and Discharge Carer Support. This creates confusion for carers and forces them to repeat themselves when undergoing assessments.

- Providers have also fed back that the complexity of the carers they are seeing has increased especially with regards to carers of patients with mental health problems and victims/survivors of domestic abuse.

- The waiting time for adult social care, from contact assessment to Carers Assessments, is several months. Whilst carers identify this as a waiting time for Respite, the issue isn't the capacity of respite it's capacity in the Community teams. ASC have identified that there are no particular capacity issues within the respite services they refer into, and that the longer waiting times are between contacting ASC and receiving non-urgent assessment. Note: Urgent assessments take place through the Rapid Response team within 48 hours; non-urgent assessments take place through the Community team and can incur waiting times of 2-3 months.

- Due to the pressures in social services there can be waiting times in Adult Social Care (ASC) of several months for non-urgent assessments. The Carers First service carries out Carers Assessments of behalf of Nottingham City Council. Whilst this was intended to alleviate pressure in ASC the numbers of carers having assessments through Carers First are much lower than anticipated. This is partly due to lack of promotion of assessments by providers, and partly that the assessment may well have no actual outcome that the carer values. This is in line with other local authorities' experiences nationally. Carers UK data shows that nearly 60% of carers are turning down the offer of an assessment. Many carers are also unsure what an

assessment involves and perhaps mistakenly see it as some kind of test that must be passed or a judgement on their ability to look after someone.

- Carers identify that the need for respite is a high priority; however uptake of respite through the commissioned pre-eligibility pathway is low. Uptake of respite through ASC and the Dementia and End of Life (EoL) pathways indicate that there are issues with the operation of this pathway and that the balance of capacity in the respite services isn't correct.

- Engagement with carers and carer support services is variable across healthcare providers, GP practices, care providers and schools. These organisations have a key role to play in identifying, signposting and supporting carers. An emphasis has been placed on Primary Care to help identify carers as the GP practice is usually the first place they present. The Primary Care Carers Support Service has been proactive in supporting Primary Care however the uptake of this support is variable across practices. In consultations, carers stated they were particularly dissatisfied with the level of support provided to carers of citizens with mental health problems and this may be an area that future providers need to upskill their staff in.

- Young carers are a particularly vulnerable group who can experience substantial physical, emotional or social problems, and encounter difficulties in school and elsewhere. Young carers have significantly lower educational attainment at GCSE level, and are more likely than the national average to be not in education, employment or training (NEET) between the ages of 16 and 19 (Children's Society, 2013). Young carers often miss out on key aspects of childhood and development such as socializing with peers. Families where there is a young carer are often reluctant to seek support due to fear of perceived failure and intrusion/family separation by services. Schools have a particular role in supporting carers aged less than 18 years; young carers report that support varies widely.

- An area of concern that has been raised in some areas relates to how we support young carers where the cared-for person is below the eligibility threshold for support from social services. In practice it does not appear that this has ever occurred within our processes. Were this situation to occur, the assessment would be revisited to ensure that no child is being left with an inappropriate caring role. Where the cared-for person refuses support and intends the child to provide support beyond what is deemed appropriate, this may become a safeguarding issue.

- Schools have a particular role in supporting carers aged less than 18 years; young carers report that support from schools varies widely, and that their requests for additional time and flexibility are often 'not taken seriously'. Whilst some schools works closely with Action for Young Carers, referring young carers to the service for support, others can be reluctant to acknowledge this issue, and support can be dependent on individual teachers' areas of concern. Local intelligence suggests that the hard to reach areas are Lenton and Hyson Green. More work is needed with schools in these areas.

- As they each maturity, young adult carers are known to disengage from young carers support, but not to engage with adult services. A number of flexible engagement options have been trialled in Nottingham and Nottinghamshire; no single model for supporting this cohort has been particularly successful. Some colleges and

universities are proactive in identifying students who are carers but this is not common to all further/higher education. Employment opportunities are available but like all support for young adult carers they appear to be inconsistent. Young adult carers who are NEET are particularly likely to lack support, and there is little information available on the scale of this issue locally.

- Carers identify that fears about what would happen to the cared-for person if they became unable to provide care have a significant impact on the carer's emotional health and wellbeing. However 83% of carers who care for a son or daughter living with them have not planned for when they are no longer able to deliver care, and 56% of carers aged over 70 whose son or daughter lives with them have not planned for when they are no longer able to care.

- In Adult Social Care, carers are regularly included in determining support for the cared-for citizen. However carers' involvement often ends after the cared-for citizen is referred to their care provider. Many care support agencies (day/evening care, residential) don't communicate with the carers if the cared-for person has mental capacity to make decisions about their own care and support. There are often disparities between carers' expectations of support agencies, and what the support agency are actually doing. This can lead to misunderstandings about care, aspects of care not being carried out at all, and in some cases lack of support on release from residential settings.

  For example, where the cared-for citizen prefers to be in their own home but the carer is unable to fully support them in the home. This is a recurring theme throughout primary and secondary care, especially within mental health services although community services for people with long term conditions are working towards being more carer friendly.

- Many carers of working age feel forced to give up work due to caring responsibilities, and many find it difficult to return. Carers often experience considerable financial hardship, a fifth of carers who reduce their working hours being £10-15k a year worse off and a further fifth losing around £15-20k annually. Many older working carers aged 55-64 years of age are likely to lose at least £30k a year.

- Due to the variations in data recording systems and associated practices across the huge number of organisations supporting cared-for citizens, it's not always currently possible to trace the carer through the records of the cared-for citizen, and link them together to co-ordinate support.

- A key issue identified during consultations is City/County divide. Carers have requested that we provide a single contact point for both city and county. It's recognised that Nottinghamshire County Council have recently commissioned a carer support hub, jointly with the County CCGs. This service began to operate in August 2015 and the contract is likely to remain in place for approximately 4 more years. In practice this has been a significant piece of work for Nottinghamshire County Council, which they would be unlikely to wish to revisit prior to this, so commissioning a single service isn't logistically viable at this time.

9) Knowledge gaps

- The numbers of carers having assessments in 2015-16 was much lower than the number of carers who identified themselves through the 2011 Census so no

meaningful comparison between the two datasets could be made. This meant that it wasn't possible to identify any differences in population groups who reported themselves as carers in the Census and those receiving carers' assessments.

- Limited information on access to respite was available through Adult Residential Services, and the information available was very difficult to interpret. Further support from Adult Residential Services would have been of additional benefit in understanding the available data.

- Very little information is available on the degree of support provided to carers by the Community Rehabilitation Day Centre and Dementia Support services. These services work primarily with the cared-for person, and have not recorded work to support the carers directly. This means it is not possible to assess the added value these services provide by supporting carers.

- Care Co-ordinators do not currently identify carers via e-healthscope etc. as they do not have the means to do this. Carer issues were addressed during MDT meetings and discussions with community teams to signpost these individuals on to the Primary Care Carers Support Service, Carers Federation etc. In addition to this, the Self-Care pilot has helped to identify carers, as they would often be referred through via social prescriptions or spoken to throughout the referral process to assist the patient (cared for). The team have reported that a number of carers' services take a long time to respond to queries and often some of them would not respond at all.

- It's currently not possible to cross-reference information on young carers with education information, for example school grades achieved by young carers compared to local and national averages.

What should we do next?

10) Recommendations for consideration by commissioners

Recommendations for consideration as part of 2016 recommissioning

- Carers often remain 'hidden' from services and thus don't access the support they need. All professionals should attempt to recognise those with caring responsibilities and signpost them to appropriate support.

- Commission a true 'single point of contact' hub jointly between Health & Social Care, to improve awareness of support available, both to carers and the professionals who can help to identify them. A single point of contact would simplify the process by which professionals can refer, and therefore increase the likelihood that they would do so. The hub should
    - Focus on outreach and promotion, to increase the widespread understanding of what being a carer is, and where to go for support, and to improve uptake and awareness of carers assessments, engagement with community services, and emergency planning
    - Work with a range of appropriate voluntary/community groups to ensure uptake of services reflects the level of need in the population
    - Providers should have appropriate training and expertise in delivering culturally specific care, and employ a diverse workforce to reflect the needs of the population in Nottingham City

  - Provide training on coping with the caring role and including general information (for carers), and training on how to support carers (for professionals working with the cared-for citizen). In addition the hub should develop a network of other providers who provide specific training relating to the condition of the cared-for citizen, and other specific needs that are provided through existing Healthcare organisations such as first aid and infection control.
  - Identify any gaps in provision

- Widespread outreach and promotion should be a core function of the service, to increase the understanding of what being a carer is as well as where to go for support. Included in the service model should be both capacity for and expectation of carrying out a significantly increased number of Carers' Assessments on behalf of the Local Authority.

- Clear expectations (and emphasis) should be placed on the hub to ensure access of the service for people for BME communities, including arrangements for managing performance. Examples of good practice for engagement with / support for BME groups should be included in the specification in order to set the level of expectation.

- Continue to provide respite to citizens identified through social services as eligible, through Adult Residential Services, as this is an ongoing need. Provide a free inclusive respite service, in line with demand, for carers who are:
  - Not in receipt of ASC respite,
  - Are on the ASC waiting list but with a high level of need/emergency,
  - Carers of patients deemed to be within the last 12 months of life in accordance with the Nottinghamshire End of Life Care Pathway (2009)

  The respite service should be managed through the Hub, and should include weekend, week day and evening support, activities/sitting service the cared-for person, specific respite for citizens with LD and mental health conditions.

- Training and support is needed to improve how agencies such as healthcare providers, GP practices, care providers and schools identify, support and work with carers. Health professionals should be provided with training on identifying carers, particularly young carers. They should be informed of the young carer services and be able to access the young carer service website. Health professionals, including GPs, should be encouraged to attend 'team around the child', priority family and CAF meetings. Providers of the young carers' service should be invited to health provider meetings. Consider developing CQUIN measures for services that support the cared-for person to encourage these services to offer advice, training, etc. to carers as part of the support for the person that they are caring for. Work with providers to develop the market in respite/short break options for citizens with LD and mental health problems.

- Retain a separate Young Carer support service, which specialises in understanding and supporting the needs of young carers, and which must also have strong links to the Carers Hub. Young carers report that they would not be comfortable seeking support alongside adult carers, and would be unlikely to attend groups or share their feelings with an adult cohort. The young carers' service must include social activities to give young carers opportunities to enjoy themselves with peers, and time away from caring responsibilities.

- Continue to include the requirement for outreach work in the Young Carers' service. The service should focus on increased outreach and capacity, and should work specifically with schools as well as Health and Social Care professionals, to improve the identification and support of young carers.
  Utilise our influence in education to improve support for young carers' through schools.

- In the Carers Hub and the Young Carers service commissioning, include the requirement for the services to work together to develop a pathway for supporting young adult carers, which is flexible and meets the needs of the individual, to avoid natural drop-off from services in mid-late teens.

- Implement Carers ID cards for carers of all ages. These cards should be pre-arranged with carer and cared-for citizen and could include permissions from the cared-for person, to 'go on record' in order to be recognised by health and care professionals as someone with whom information can be shared. This could allow professionals to speak to the carer should the cared-for citizen be ill or otherwise unavailable, as well as serving as identification if the carer's status needs to be verified. The card would also, in the event of an emergency, alert the finder to the presence of a person with support needs, who is not now being looked after. The finder could then contact the emergency contact listed on the card, and the Hub to aid enacting the emergency plan. This would provide re-assurance for both the carer and the cared-for citizen.

Further recommendations

- Utilise all of the resources within our communities and not just rely on specifically commissioned services to support carers. The greatest improvements for carers will be made by improving engagement of organisations that support the cared-for citizen (Primary care, care agencies, community healthcare teams, pharmacies etc.). Look at opportunities to include the requirement to work with carers in all relevant contracts.

- Improve systems for recording data across health and social care, linking the carer and the cared-for citizen to improve reporting of issues affecting carers at individual and population level, and assist in organisations in providing co-ordinated support.

- Consider how other departments/organisations can help to reduce financial impact of caring, for example through discounted wellbeing services, reduced cost transport, hospital parking and free/low cost activities.

- Work with local employers and education establishments to become more carer-friendly. Examples could include a recognised 'Carer Friendly' business standard building on the success of the 'Dementia-friendly Communities' model.

- Explore opportunities for joint arrangements with County. For example a reciprocal arrangement where both City and County hubs hold each other's contact number. Nottinghamshire County Council have a 'golden number', a single number for all customer service queries, and there is a single number for the County carer's hub. If we were to move to a similar model, i.e. NHCP and a single carer hub, we would also

be in a position to look at being able to signpost, and ideally transfer citizens between organisations.

Data and information

- Implement better recording of information from carers assessments including reducing the number of 'not known' recordings in categories.

- The number of carers supported via providing increased support to the cared for person. It has been noted that a number of the referrals made to the Nottingham Health and Care Point by healthcare professionals are to support the cared for person and there is no record that this referral is also indirectly supporting the carer. This data could be captured going forwards and it has highlighted a training gap within health as this is a missed opportunity for staff to refer a carer for a carers' assessment, where appropriate.

- Collect better information on young carers. Specifically, demographic information on age, gender, ethnicity etc. The definition of young carers is aged under 18, whereas census information breaks carers down into ages 15 and under, and 16-24.

- Explore opportunities to link information on education and employment to caring status, to demonstrate the impact of the caring role on young carers and young adult carers. For example what % of young carers are NEET? School grades achieved by young carers compared to local and national averages?

- Recording the reason the carer refuses an assessment – this is being undertaken through Carers Federation in 2016, but would be useful to record through ASC.

Appendix

Nottinghamshire County

Nottinghamshire County has a Carers' Hub, jointly commissioned by Nottinghamshire County Council and the six CCGs within the county. The hub offers information, advice and guidance, signposting to other organisations; carers groups and drop-ins; peer support; access to free training, health and well-being memberships, and carers' benefits and discounts. The Hub also offers access to holiday lodges for breaks, and Carers Grants, depending on eligibility. The Hub don't offer statutory Carers Assessments, they signpost carers to Local Authority assessments through the single point of contact.

Support services are available for young carers, however they are provided separately and availability of services differs dependant on which area the carer is resident in. Social care support or young carers is comparable to that in Nottingham City.

Depending on the level of need identified in the carers' assessment, Nottinghamshire County Council offer a direct payment to carers with high or extremely high needs. Approximately 44% of carers who have statutory assessments meet threshold criteria for a direct payment.

Respite criteria in Nottinghamshire County are the same as for high needs or extremely high needs.

To be eligible for carers' support in Nottinghamshire County, both the carer and the cared-for person must be registered with a GP in one of the six CCGs.

Birmingham City

The Forward Carers service in Birmingham is funded by Birmingham City Council, and provided by a consortium of around 30 community and voluntary organisations, schools and social enterprises. The Hub includes all carer support in the city, including Short breaks for disabled children, which amount to approx. 50% of contract value. The hub includes a telephone and website service allowing carers to access information, advice and support, one to one support on welfare entitlements and counselling, support groups, wellbeing provision including mindfulness, respite including Short Breaks, out of school activities for children with additional support needs, training for carers, and signposting to other agencies who can assist carers, and online communities through social media.

As with Nottingham City, Birmingham is home to highly diverse communities. One of the advantages of the consortium is that it includes organisations which work specifically with communities to ensure engagement. The Hub does not currently undertake statutory carers' assessments on behalf of the Local Authority. However the consortium is currently working towards this model. The Hub uses its own Wellbeing Assessment to determine what support a carer may need; as well as anything specific the carer seeks support on.
Birmingham City Council commissioned a separate Young Carers service called Young Carers Unite, for carers under the age of 18. The Hub has an arrangement whereby, with the young carers consent, Young Carers Unite passes their details on to the Carers Hub, so that the hub can continue to support them beyond the age of 18.

Staffordshire /Stoke

The Carers Hub was commissioned through a pooled funding arrangement between Staffordshire County and Stoke City Councils, and the 6 CCGs in the area. The service comprises 2 hubs, one in Stoke-on-Trent and one in Staffordshire, with up to 20 outreach points known as Community Spokes. Services and support provided through the hub include

info, advice & guidance, assessment (not statutory) & support planning, advocacy, emotional health and wellbeing support, peer and befriending support, crisis prevention, personal wellbeing budgets and training for both carers and professionals. Young carers' targeted provision is linked through the hub.

The hub is also responsible for promotion and awareness-raising. In Staffordshire the assessments for Young Carers are carried out via the Hub, in Stoke Young Carers assessments are carried out by the Council and then the Carers Hub follows them up. A Young Adult Carers service for 16-25s is under development.

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