

Joint strategic needs assessment - Carers (2017)

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

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- 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 reach 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.