

# Carers in Sheffield Health Needs Assessment

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## **Contents**

### **1. Executive Summary**

- 1.1. Introduction
- 1.2. Background
- 1.3. Methodology
- 1.4. Findings
- 1.5. Interventions for Carers
- 1.6. Current Gaps in Identification
- 1.7. Equity in Accessing Carers Services
- 1.8. Future Commissioning for Carer Support
- 1.9. Recommendations
- 1.10. Acknowledgements

### **2. Introduction**

- 2.1 Rationale
- 2.2 Future Services and Commissioning
- 2.3 Definition of a Carer

### **3. Aims and Objectives of this Health Needs Assessment**

- 3.1. Aims
- 3.2. Objectives

### **4. Government Policy on Carers**

- 4.1. National Policy
- 4.2. Local Policy

### **5. Methodology and Data Sources**

- 5.1. Literature Review
- 5.2. Data Sources

### **6. Findings on Caring and Health**

- 6.1. Geographical Distribution of Resident Informal Carers in Sheffield
- 6.2. Geographical Distribution of Carers known to Sheffield Carers Centre
- 6.3. Estimates of Prevalence of Informal Caring
- 6.4. Projected Prevalence of Informal Caring in Sheffield
- 6.5. Carer Prevalence in Practice Consortia
- 6.6. Incidence of Informal Caring in Sheffield
- 6.7. Age and Onset of Informal Caring in Sheffield
- 6.8. Hours of Caring by Informal Carers in Sheffield
- 6.9. National and Local Evidence on Risks to Health Associated with Caring
- 6.10. Caring and Mental Health
- 6.11. Wider Impacts of Caring
- 6.12. Particular Risks for Young Carers
- 6.13. Carers' Access to Statutory and Voluntary Sector Services in Sheffield

### **7. Interventions for Adult and Young Carers**

- 7.1. Spend on Carer Support
- 7.2. Carer Interventions in Table 11
- 7.3. Good Practice in Carers Support Interventions in Sheffield
- 7.4. Interventions in Primary Care

- 7.5. Flexible Planned Breaks Service
  - 7.6. Peer Support Groups
  - 7.7. Carer Education Programmes
  - 7.8. Assistive Technology
8. Evidence on Return on Investment and Social Return on Investment of Carer Interventions
- 8.1. Return on Investment
  - 8.2. National Carers Strategy Demonstrator Sites
  - 8.3. Dementia
  - 8.4. Carers Centres National Report
  - 8.5. Interventions for Young Carers
  - 8.6. Recommendations for Commissioning Carer Interventions
9. Current Gaps in Identification
- 9.1. Identification of Carers in Adults and Children's Services
  - 9.2. Evidence on Carers Interventions in Primary Care
10. Equity In Accessing Services
- 10.1. Support Services for Black and Ethnic Carers
  - 10.2. Support Services for Male Carers
11. Future Commissioning for Carer Support
- 11.1. Voluntary Sector
  - 11.2. Self Directed Support
  - 11.3. Practice Based Commissioning
12. Recommendations
- 12.1. General Recommendations
  - 12.2. Commissioning Recommendations

Appendix 1 References

Appendix 2 List of Maps, Graphs and Tables

## **1. Executive Summary**

### **1.1. Introduction**

This health needs assessment on caring in Sheffield intends to present an assessment of carers health needs across the city, whether statutory and voluntary sector services are meeting those needs and recommendations for commissioning of carers support in the future. This assessment aims to estimate current and future numbers of people caring in Sheffield, to summarise evidence on the health needs of carers and the take up of services by carers. It aims to inform the Carers and Young Carers Board, the Joint Strategic Needs Assessment Reference Group and to inform future commissioning of carers services.

### **1.2. Background**

Previously there has been no health needs assessment of adult and young carers in Sheffield and this assessment aims to gather the available evidence nationally and locally to build on the evidence base and gain a fuller picture of caring in the city.

Carers issues have come to the forefront of health and social care policy in recent years and publication of the 2008 National Carers Strategy (1) and locally the Sheffield Citywide Carers Strategy 2010 -2013 (2) have ensured that carers needs are recognised in Sheffield at a strategic level. The recent formation of the Sheffield Carers and Young Carers Board to implement the local strategy is also providing a strategic voice for carers in the city. Fundamental changes are imminent in how health and social care will be commissioned and delivered in the future. The advent of 'self directed support' or 'personalisation' and of GP Clinical Commissioning Consortia (GPCCC) and how this will impact on carers is also considered in this health needs assessment.

### **1.3. Methodology**

First steps were to undertake a literature search on other health needs assessments on carers. Data was taken from a number of national and local sources to calculate prevalence and incidence of adult and young carers in Sheffield. These were the 2001 Census, (3) General Household Survey (GHS) Survey 2000, (4) Household Survey 2009/10 (5), Sheffield Health and Illness Prevalence Survey (SHAIPS) 2002 (6) and the Sheffield City Council Care First database (7). Data from practice registers and current providers was also collated to build a picture of carer numbers in Sheffield. The same data was used to examine age, onset and hours of caring in Sheffield.

National and local studies were examined to gather evidence on the impact of caring on mental and physical health, and on opportunities to education and employment, particularly in relation to young carers. Again national and local studies were used to determine the effectiveness of a range of interventions for carers in Sheffield and the return on investment for those. Current gaps in the identification of certain groups of carers in Sheffield and if they access services was examined using national and local data. Finally national and local evidence on carer interventions was used to form the basis of recommendations in commissioning local carer support in the future.

### **1.4. Findings**

The findings of this health needs assessment confirm previous findings of a link between individuals caring and being at *greater risk* of experiencing adverse physical and mental health, than the non caring population. Furthermore, the *increased risk* of experiencing, *in particular*, mental ill health is evident when caring is intense and when someone is caring for long hours per week (8,9, 10). The main findings from the data and studies show:

- Similar estimated prevalence of carers in Sheffield from national data sets (Census 2001, GHS 2000 and Household Survey 2009/10).
- There is *likely* to be unmet carer need within Practice Consortia as prevalence of carers on practice registers is lower in comparison to estimated national prevalence.
- The prevalence of caring increases with age, in line with growing numbers of older people.
- Numbers of young carers in the city is unknown, due to issues of stigma and identification.
- Caring can be positive for health, however, carers are at greater risk of experiencing ill health as part of general health inequalities.

- Carers providing intense caring for long hours (more than 20 hours per week) are at *particular risk* of experiencing mental ill health.
- There are wider impacts of caring for adult carers in relation to staying in employment and an increased likelihood of poverty in retirement.
- Young carers are at *particular risk* from experiencing health inequalities *earlier* that are specifically educational and work related.

### 1.5. Interventions for Carers

NHS Sheffield and Sheffield City Council currently commission a range of interventions for carers from the voluntary and statutory sector. Investing in carers support is seen as important by partners across the city, as carers contribute significantly to the local health and social care economy. Investing in support to younger carers can contribute greatly towards improving the emotional wellbeing of children and young people and helping young people to stay in education and employment (11).

Good practice in carer support in Sheffield is examined in respect of national evidence on the effectiveness of carer interventions. The evidence base for both voluntary and statutory interventions is presented and recommendations made about what should continue to be commissioned by NHS Sheffield, Sheffield City Council and Clinical Commissioning Consortia in the future.

Interventions that effectively support carers in Sheffield range from proactive and responsive support in GP practices, to the flexible planned breaks service, peer support groups, carer education programmes and assistive technology.

Nationally there is little evidence that demonstrates a quantifiable return on investment from investing in carer support (12). The recent report from the evaluation of the National Carers Strategy Demonstrator Sites highlights evidence showing the positive effect of interventions for adult carers within primary care (13). The report also presents findings on how carer support in some cases has contributed to preventing an emergency admission to hospital or residential care.

There is some evidence for Social Return on Investment (SROI) via adult carers interventions within Carers Centres. A recent report from the Princess Royal Trust for Carers outlines the long term benefits and SROI of carer support via Carers Centres. The evidence base on the financial and SROI for *young carer* interventions is stronger and factors in the value of preventative work on young peoples' future life course. Research demonstrates how supporting young carers has long term benefits for them and is an effective preventative measure to reduce the potential long term negative impact of caring (14).

### 1.6. Current Gaps in Identification

There needs to be an increase in the identification of young carers, black and minority ethnic (BME) carers, young adult carers, male carers and migrant carers to ascertain unmet need. A lack of data nationally and locally from statutory organisations such as schools and GP surgeries on numbers of young carers is a significant gap. In particular there is inconsistent awareness of, identification of and support of young carers within schools and GP surgeries across the city.

### 1.7. Equity in Accessing Carers Services

There is likely to be a level of unmet need for carers within BME communities, male carers, young adult carers and young carers, due to lack of identification. Quarterly service data from carer support services show that BME carers, male carers and young adult carers are a small percentage of service users and are not accessing support, to the same degree as other groups of carers.

BME carers may not be accessing support due to cultural beliefs, language barriers, or a lack of culturally appropriate services for the carer and cared for person. For male carers, other reasons could be that current carers services are not perceived to be 'male friendly' or do not cater for men's and young adult carers needs.

## **1.8. Future Commissioning for Carer Support**

Part of the rationale behind this health needs assessment was to present an overall picture of current carer services for future commissioners in view of imminent change in the commissioning of carers support. An assessment of what is effective for carers in Sheffield and where possible what is cost effective provides a rationale and business case for commissioning carer support in the future.

Voluntary sector services to carers will be required to competitively tender for contracts in the future and may need to combine their resources, such as forming a consortium, to deliver a service to carers. The increased roll out of self directed support as part of personal budgets for service users may also affect how carers access support. The increased commissioning powers of GP Clinical Commissioning Consortia (GPCCC) could also influence how carers are supported within primary care.

## **1.9. Recommendations**

Based on national and local evidence it is recommended that NHS Sheffield and Sheffield City Council continue to commission a range of support interventions for adult and young carers through the voluntary sector. For NHS Sheffield, statutory support to carers within primary care needs to be developed and embedded within new clinical commissioning arrangements so that is sustained on a long term basis.

## **1.10. Acknowledgments**

I would like to thank the NHS Sheffield Public Health Analysis Team, in particular Ann Richardson, and Georgina Anderson. For assistance in literature searches the NHS Sheffield Library Team and in particular Ann Tanker and Richard Carey.

Colleagues at the City Council have also contributed towards this work, and voluntary sector organisations have kindly contributed data to support analysis of carer support in the city. I would also like to thank NHS colleagues and specifically my manager, Sheila Paul, for her guidance throughout this work.

## **2. Introduction**

### **2.1. Rationale**

This health needs assessment aims to present evidence on the health needs of carers, estimate current and future numbers of adult and young carers in Sheffield and present uptake of voluntary sector services for carers in Sheffield. It is intended to contribute towards NHS Sheffield's review of commissioned carer services; the objectives of the Carers and Young Carers Board; the work of the Joint Strategic Needs Assessment (JSNA) Reference Group and to inform future commissioning partners such as GP Clinical Commissioning Consortia (GPCCC), NHS Sheffield and Sheffield City Council.

Nationally the publication of the National Carers Strategy in 2008<sup>(15)</sup> and the 2010 refresh of this<sup>(16)</sup> demonstrates carers issues are a key concern for the Coalition Government. The strategy highlights the need to build on the evidence base on carers to inform future commissioning of services.

The recent publication of the Sheffield Citywide Carers Strategy 2010 – 2013<sup>(17)</sup> and the establishment of the Carers and Young Carers Partnership Board in 2010 has raised carers issues to a strategic level in the city. The Carers and Young Carers Board provides a forum to disseminate local evidence and good practice that informs local commissioning of services for carers in Sheffield.

In Sheffield, there has been no needs assessment undertaken previously on carers and the potential impact that caring and long term caring has on an individual's mental and physical health has emerged as a serious issue in relation to health inequalities over the last decade<sup>(18)</sup>.

Furthermore carers issues, and in particular the impact of caring on mental and physical health, has come to the forefront of local policy in Sheffield. Carers contribute greatly to the health and social care economy in Sheffield by supporting a significant proportion of ill and vulnerable citizens (19). It is recognised that informal carers save the local health and social care economy a substantial amount of money. It is estimated that informal caring saves Sheffield £2,315 million per annum (20). This is a substantial saving and is likely to increase as the population ages and people are living longer with ill health or disability (21).

Furthermore, this health needs assessment is within the context of imminent change to the way voluntary sector services will be commissioned by Sheffield City Council and the NHS or GP Clinical Commissioning Consortia in the future. Greater clarity is needed on whether the services we commission are meeting carers' needs across the city.

Major social and demographic changes will take place over the next decade (22) and to meet this in a challenging economic environment, commissioned services that support carers will need to demonstrate they are cost effective and delivered accordingly as part of a robust evidence base. It is important that the voluntary sector delivers effective and appropriate support to carers. This health needs assessments of carers is intended to contribute towards Sheffield City Council and NHS Sheffield's review of commissioned voluntary sector services for carers.

## **2.2. Future Services and Commissioning**

This health needs assessment also takes place within the gradual rollout of self directed support within health and social care. Under government directives self directed support, will play a much stronger role in the future, in how patients and their carers will access support (23). This is likely to have an effect on carers themselves, as well as voluntary and statutory sector providers. Alongside this, newly formed GP Clinical Commissioning Consortia may also need to consider how they commission services for carers and it is hoped this health needs assessment can contribute towards the knowledge base on carer need in the city.

## **2.3. Definition of a carer**

A carer is defined by the Department of Health as someone who;

*'Spends a significant proportion of their life providing unpaid support to family or friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has a mental health or substance misuse problem'. (24)*

There is no agreed definition of a young carer, however, the Social Care Institute for Excellence (SCIE) defines a young carer as;

*'children and young persons under 18 who provide, or intend to provide care, assistance or support to another family member. They carry out often on a regular basis significant or substantial caring tasks'. (25)*

## **3. Aims and Objectives of this Health Needs Assessment**

### **3.1. Aims**

The aims of this health needs assessment are:

- To estimate the current and future numbers of adult and young carers in Sheffield, with respect to caring based on available evidence.
- To present and summarise evidence on the health needs of carers and the take up of carers services in Sheffield.
- To inform the Carers and Young Carers Board and the Joint Strategic Needs Assessment Reference Group.
- To inform future commissioners of carers voluntary and statutory sector services, such as GP Clinical Commissioning Consortia, NHS Sheffield and Sheffield City Council.

### **3.2. Objectives**

This health needs assessment presents:

- Synthetic estimates of the prevalence of caring in Sheffield.
- Synthetic estimates of projected numbers of carers in Sheffield from 2010 to 2015.
- Collated evidence on whether there is an association between long hours of caring and physical and mental ill health.
- Evidence on positive and negative aspects of caring with respect to mental and physical health.
- Patterns and uptake of primary care and voluntary sector services in Sheffield, where these are known.
- Evidence on the effectiveness of interventions for carers in Sheffield and local good practice.
- Findings on current gaps within carer support services in Sheffield and the future landscape of commissioning carer services.
- Recommendations for future commissioners as a result of the findings.

This health needs assessment is exploratory. It is to be noted that recommendations from this needs assessment are made in the current climate of restricted budgets, financial uncertainty and a fundamentally changing commissioning landscape.

## **4. Government Policy on Carers**

### **4.1. National Policy**

#### **4.1.1. The Role of Carers**

Carers have increasingly come to the forefront of health and social care policy over the last fifteen years (26, 27, 28). The importance of carers roles and the impact that informal caring has on health is now increasingly recognised by government and policy makers. Health and social care policy acknowledges that carers of all ages play a vital role in contributing towards the care of people and helping them to stay at home or in the community. This is outlined in the Public Health White Paper, Healthy Lives Healthy People, Nov 2010 (29) and in A Vision for Adult Social Care 2010 (30). The imminent White Paper in Spring 2012, 'Caring for our Future Shared Ambitions for Care and Support' highlights carer support as a vital element of the future social care systems (31). Including patients and carers is seen as an important part of the commissioning process and an 'integral part of local commissioning across health and social care' (32).

Current health and social care policy highlights that informal carers need support from a variety of sources (health, social care, schools, employers) if they are to sustain their caring role and not succumb to mental or physical ill health (33, 34, 35, 36, 37).

#### **4.1.2. National Carers Strategy**

The publication of the National Carers Strategy in 2008 and the recent refresh of this - Recognised, Valued and Supported; Next Steps for the Carers Strategy 2010, acknowledges the detrimental effect that informal caring can have on carers' health and wellbeing '*There is a clear relationship between poor health and caring that increases with the duration and intensity of the caring role*' (38). Increasing awareness of young carers, the caring roles they are undertaking and the potential impact of caring responsibilities on children and young people's mental and physical health is also highlighted in government policy (39, 40).

#### **4.1.3. Key Priorities**

The four key priorities within the refresh Next Steps for the Carers Strategy 2010 (41) include 'supporting carers to remain mentally and physically well' and actions to do this are; funding over the next four years to NHS organisations to provide breaks to carers; future health and wellbeing checks for carers; expanding access to Improved Access to Psychological Therapies (IAPT) for carers; additional resources for GP training to increase GPs' awareness and understanding of carers needs for support and services.

Key messages from carers and carers organisations in response to the consultation carried out as part of the National Carers Strategy 2010 refresh were that carers often neglected their own health; needed timely advice to maintain their wellbeing; and needed regular breaks from caring to prevent exhaustion and ill health (42).

Carers who responded to the consultation also reported they were not always included in clinical discussions and that some health care professionals needed additional training to make them 'carer aware' (43). These issues raised by carers pose some key questions around the equality and inclusivity of informal carers in discussing and planning the care of their relative with health professionals.

#### **4.1.4. Changes in Commissioning Services**

Alongside this, organisational changes in the delivery of primary care services will be rolled out in the next two years. GP Clinical Commissioning Consortia could be responsible for partly commissioning carers' services in the future. Currently Sheffield City Council commission a greater proportion of carers voluntary sector support services than NHS Sheffield. It is yet to be determined whether and which voluntary sector carer support services will be commissioned by GP Clinical Commissioning Consortia. It is important that the initial identification of carers continues to be included in primary care policy and practice, as primary care plays a key role in supporting carers to look after their health.

Voluntary sector services have historically provided the majority of support to carers. Reflecting national trends, population projections for Sheffield suggest an increase in the numbers of older residents and of people with a disability or illness (44, 45). In view of this it is reasonable to assume carer burden will stay at the same level and in the near future, in a climate of increasing demand and decreasing resources, is likely to rise. Possible future cuts in funding to voluntary sector services may increase dependence on health and social care services.

### **4.2. Local Policy**

#### **4.2.1. Sheffield Carers Strategy and Partnership Board**

Locally, carers issues have taken on a strategic profile through the publication of the Sheffield Citywide Carers Strategy 2010-2013 (46). The eight priorities of the Sheffield Carers Strategy are:

- Improve joint working between organisations so that carers are better supported.
- Identify hidden carers and raise awareness of carers and their caring responsibilities within organisations and in the wider communities.
- Provide information, advice and advocacy to enable carers to make informed choices.
- Sustain carers in their caring role and prevent carer breakdown.
- Involve carers individually and collectively in shaping, commissioning, monitoring and evaluating services.
- Promote support for employees who have caring responsibilities.
- Ensure that carers have a life of their own outside of their caring role.
- Enable young carers to have the same life chances as other children and young people and prevent them from taking on inappropriate caring roles.

This has committed a number of statutory organisations to support carers and has highlighted carers issues within local strategic partnerships, such as the Sheffield First for Health and Wellbeing Board. The recent formation in 2010 of the Carers and Young Carers Partnership Board has helped to give a strategic voice and forum for carers and young carers.

#### **4.2.2. Local Health and Social Care Policy**

Carers issues have also gained momentum in NHS Sheffield and Sheffield City Council policy direction. Carers are acknowledged as important partners in care planning and commissioning services.

For NHS Sheffield and the City Council this has included looking at the needs of carers as part of service delivery pathways, such as dementia care, long term care of stroke patients, managing long term conditions and end of life and in management of those with a mental health condition (47, 48, 49).

Carers are part of local strategic partnership arrangements and sit on Partnership Boards for Mental Health, Learning Disabilities, Older People, 0-19 Partnership Board, as well as the Carers and Young Carers Board.

The Sheffield Joint Strategic Needs Assessment (JSNA) 2008 between the City Council and NHS Sheffield highlights carers as '*essential partners in providing care in the community*' (50). It pinpoints carers as a community at risk of ill health and of experiencing health inequalities (51). It also highlights in the future the growing numbers of people with a mental health condition or a learning disability who will be looked after by family carers (52).

NHS Sheffield's strategy as outlined in Achieving Balanced Health (53) acknowledges that greater support is needed for carers, particularly those looking after people with dementia and learning disabilities (54).

#### **4.2.3. Self Directed Support**

There are changes in the way carers services are being commissioned. These include 'personalisation' (55) as a way of delivering health and social care services to people. The increasing use of 'personalisation' or self directed support (SDS) within social care and imminently in healthcare and how this will affect carers is currently being explored in a number of policy documents (56). As Sheffield City Council rolls out personal budgets within its support services the practical impact of personalisation for service users and their carers is yet to be seen.

### **5. Methodology and Data Sources**

#### **5.1. Literature Review**

##### **5.1.1. Health Needs Assessments**

A literature review was undertaken to identify any other health needs assessments on carers, any UK based studies on the prevalence and incidence of caring and to look at research on the effectiveness and cost effectiveness of carer interventions.

The NHS Sheffield library team undertook a literature search on the following databases: EMBASE; MEDLINE; CINAHL; BNI. Websites that were looked at were: Office of National Statistics (ONS); National Institute of Clinical Excellence (NICE); Carers UK; Department of Health (DH); Social Care Institute for Excellence (SCIE); National Young Carers Coalition (NYCC); Royal College of General Physicians (RCGP).

This established that very few health needs assessments on carers had been done, with the exception of a comprehensive study, as part of a Joint Strategic Needs Assessment, by Lancashire County Council (57).

##### **5.1.2. Studies on Carer Prevalence and Incidence**

There were few UK studies on carer prevalence or incidence, with the exception of a study by Carers UK, It Could Be You, (58) that estimates national carer incidence annually over the next twenty five years and particularly in relation to the growing numbers of older people. Carers UK have produced a factsheet estimating the prevalence of caring (59) and carer prevalence within practice populations has been estimated by the Royal College of Physicians and the Princess Royal Trust for Carers (PRTC) as part of their guidance to primary care teams (60).

### **5.1.3. Studies on Carer Interventions**

There were very few systematic reviews summarising the effectiveness of carers interventions, such as support groups, planned breaks or carer education programmes. Two recent systematic reviews that were found were, Victor, E (2009) A Systematic Review of Interventions for Carers in the UK by the PRTC and Nottingham University (61). This presents a comprehensive overview of carers interventions across a spectrum, ranging from befriending schemes, to training for carers and counselling programmes.

### **5.1.4. Studies on Return on Investment and Social Return on Investment**

There were few studies looking at the cost effectiveness or the reduction in the use of health services as a result of investing in carer support. There were numerous small scale studies both national and international looking at the varying effectiveness of carer interventions across a wide range of disease areas and groups of carers. The majority of these small studies *did not* address the question of return on investment and those that did were inconclusive in their findings due to study design and methodology.

A study by the Audit Commission in 2004 (62) looked at the cost effectiveness of a variety of adult carer interventions, with inconclusive findings. The National Carers Demonstrator Sites final report (63) presents stronger evidence on the positive impact of adult carer support on emergency admissions to hospital and residential care.

A recent study looks at the Social Return on Investment (SROI) in carer support via Carers Centres. The Investment In Carers Centres Report 2011 by Baker Tilly and the Princess Royal Trust for Carers presents positive evidence on the total life course benefits and gains of carer interventions (64).

One significant study by the PRTC, Crossroads and Manchester Metropolitan University (65) on the Return on Investment and the SROI for young carers interventions was found. This presented strong evidence of the positive impact of support for young carers in increasing their educational, economic and social opportunities.

## **5.2. Data Sources**

### **5.2.1. National and Local Data Sources**

The estimated numbers of adult and young carers in Sheffield are based on the most comprehensive and robust data sources available. These are limited to the 2001 Census (66) the General Household Survey (GHS) from 2000 (67) Survey of Carers in Households 2009/10 (68) the Sheffield Health and Illness Prevalence Survey 2002 (SHAIPS) (69) and the Sheffield City Council Care First database 2011 (70).

Calculating estimates of the numbers of young carers under 18 years old in Sheffield's population was done using the same data from the 2001 Census (71) and more recently from a Nottingham University Survey in 2010 (72).

The projected number of carers from 2010 to 2015 was calculated by assuming the current rate of caring remains constant and applying the estimated prevalence of caring to population projections for Sheffield in 2015. Data on Sheffield's population and projected population estimates was accessed on NHS Sheffield Health Data Online (SHOO) intranet (73).

### **5.2.2. Data Tools**

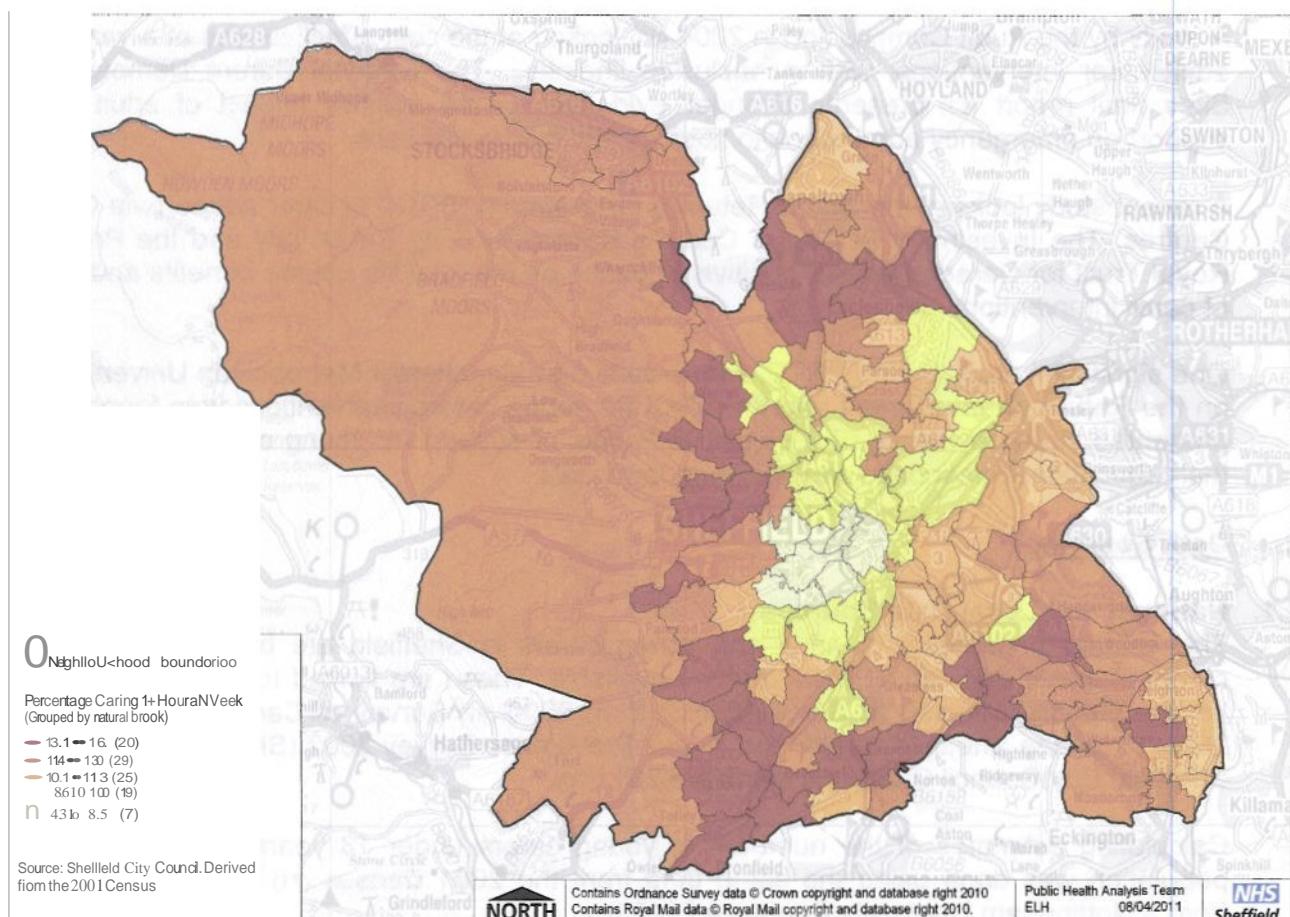
Geographical maps, graphs, pie charts, bar charts and tables were formulated using data from the following; Report of the Sheffield Health and Illness Prevalence Survey (SHAIPS) March 2002, SHA and Sheffield PCT's; Office National Statistics (ONS) 2001 Census; Sheffield Carers Centre client database; GP Commissioning Consortia Practice Registers of Carers; Voluntary Sector Organisations Quarterly data and Equality Impact Assessments data from May 2011.

## 6. Findings on Caring and Health

To gain an overall picture of informal caring in Sheffield this section includes the following:<sup>p12</sup> Geographical Distribution of Resident Informal Carers; **p13** Geographical Distribution of Informal Carers known to Sheffield Carers Centre; Estimates of Prevalence of Informal Caring; **p14** Projected Prevalence of Informal Caring; **p15** Carer Prevalence in Practice Consortia; **p16** Incidence of Informal Caring; Age and Onset of Informal Caring; **p18** Hours of Informal Caring; National and Local Evidence on Risks to Health Associated with Caring; **p19** Caring and Mental Health; **p22** Wider Impacts of Caring; Particular Risks for Young Carers; **p22** Carers' Access to Statutory and Voluntary Sector Services.

### 6.1. Geographical Distribution of Resident Informal Carers in Sheffield

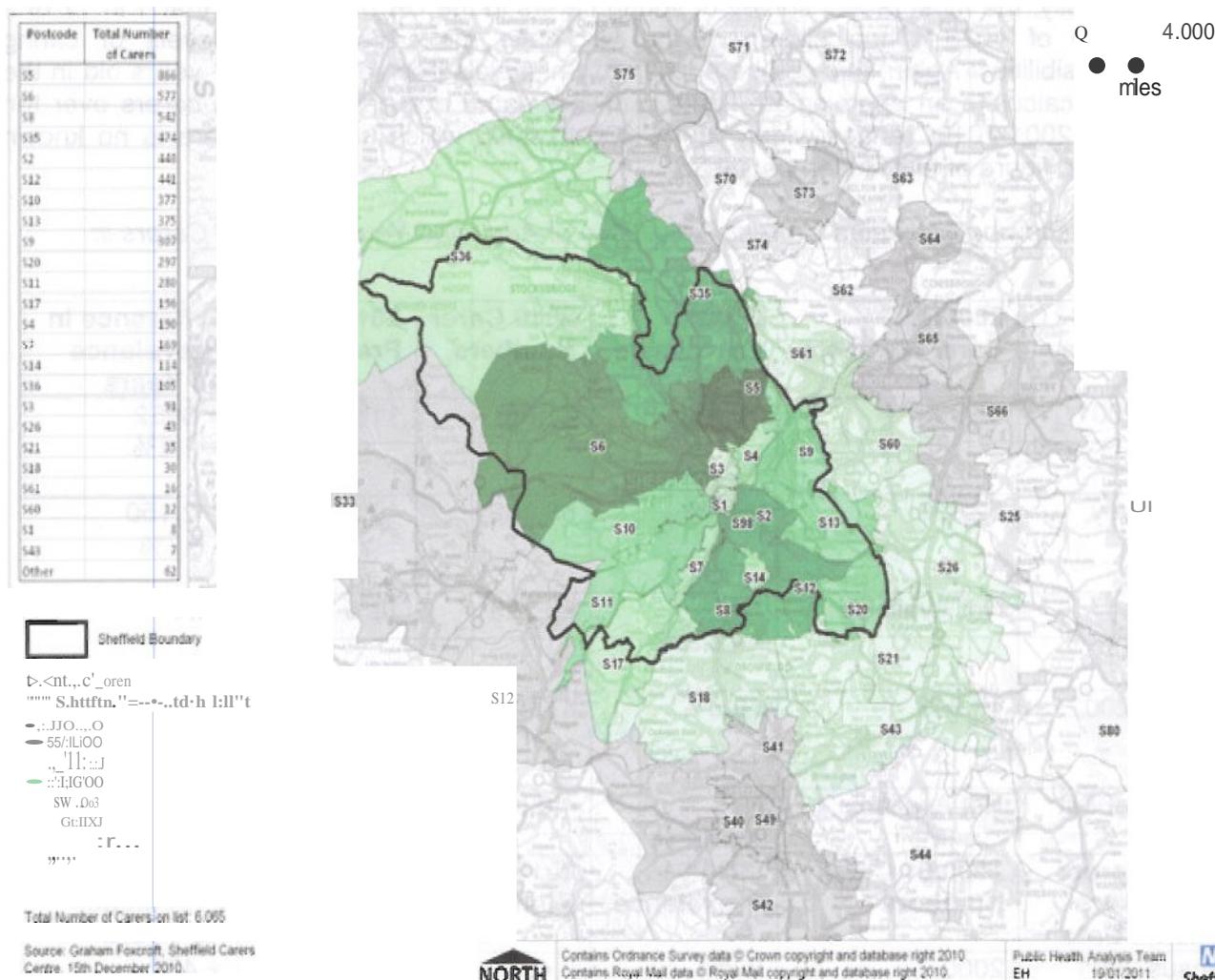
**Fig 1** Map Showing Percentage Population (All Ages) Caring 1+ Hours Per Week, by Sheffield Neighbourhood (2001)



The map above shows the geographical distribution and hours of caring of all age carers (including young carers under 18 years old) in Sheffield based on data from the 2001 Census. It shows carers who are caring for a greater number of hours are resident in Hallam and South Consortia (HASC) areas. The higher number of carer hours in the HASC area could be associated with greater numbers of older people resident in these areas who have unpaid family carers<sup>(74)</sup>.

## 6.2. Geographical Distribution of Carers known to Sheffield Carers Centre

**Fig 2** Sheffield Carers Centre – Carers on Carers Centre Database (as at December 2010) by Postcode District.



The 2001 Census asked parents or guardians, rather than children or young people to complete the question, therefore numbers of young carers may be under reported, as parents may not recognise or wish to acknowledge their children are caring for them.

Nationally, the most recent survey of young carers in the UK (77) revealed that 1 in 12 of a sample of 4029 schoolchildren in the UK have moderate to high levels of caring responsibilities. Again, this can be applied to Sheffield's population of 5-17 years old in the city to calculate an approximate figure. The estimated numbers of young carers over ten years (2001-2010) ranges widely from 2000 to 6000 which highlights there is no known baseline figure of this hidden population.

**Table 3** Table showing Estimated Current Prevalence of Adult and Young Informal Carers in Sheffield

Adult Carers National Data	2000/01 Carer Numbers	2000/01 Prevalence	2010 Carer Numbers	2010 Prevalence	Difference in Prevalence 10 Years
Census 2001	55,905	10.8%	61,957	11%	+ 6052 + 1.2%
GHS survey 2000*	52,999	16.7%	55,149	10%	+ 2,150 -6.7%
HH Survey 2009/10 *	Not Available	Not Available	56,229	12%	N/A
SHAIPS 2002	43,943	10.8%	49,995	11%	+6052 +1.2%
SCC CareFirst*	Not Available	Not Available	4,820	N/A	N/A
Young Carers under 18 yrs National Data	2000/01 Carer Numbers	2000/01 Prevalence	2010 Carer Numbers	2010 Prevalence	Difference in Prevalence 10 Years
Census 2001	2000	0.3%	2,437	2.5%	+ 437
Notts University Survey 2010	Not Available	Not Available	6,627	8.3%	N/A

General Household Survey 2000, Census 2001, Household Survey 2009/10.

Census 2001, Nottingham University Survey November 2010.

\*Carers aged 16+ years.

\* SCC CareFirst data show numbers of carers for known service users and is a low estimate.

## 6.4 Projected Prevalence of Informal Caring in Sheffield

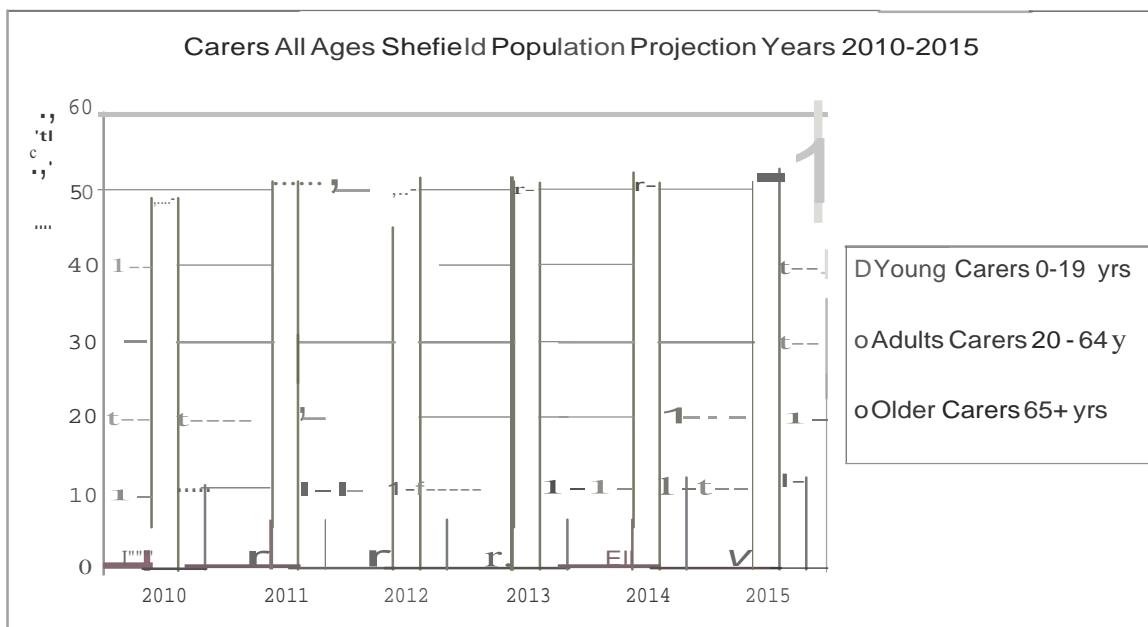
### 6.4.1. 2001 Census

Assuming that rates of caring remain constant, in the short term, from 2010 to 2015, the adult carer population could be estimated to increase to 66,715. This would see an increase of caring across all ages to 11.2% in the Sheffield population. Again, this estimation excludes the likelihood of increasing and current hidden numbers of children and teenagers, under 18 years old, who are caring and remain unknown to statutory and voluntary sector services.

**Table 4 Table showing Estimated Projected Prevalence for Sheffield Carers 2010-2015 based on 2001 Census figures.**

Age Range Carers 2001 Figures	2010%	2001 Est Number	2010 Est Number	2011 Est Number	2012 Est Number	2013 Est Number	2014 Est Number	2015 Est Number	95%CI Paramete rs
Young Carers 0-19 yrs	3.93%	2079	2436	2238	2238	2245	2256	2271	CI: 2,177-2,326
Adults Carers 20-64 yrs	78.62%	43725	48707	50764	51201	51621	52111	52583	CI: 49722-50482
Older Carers 65+ yrs	17.45%	10064	10813	11110	11339	11597	11732	11861	CI: 11045-11389
TOTAL	100%	55,868	61,956	64,112	64,778	65,463	66,099	66,715	

**Fig 6 Graph showing Current Estimation of Carers of All Ages in Sheffield for 2010- 2015 (Based on 2001 Census figures and applied to Sheffield 2010 Population).**



## 6.5. Carer Prevalence in Practice Consortia

### 6.5.1. Practice Prevalence

The number of carers registered at all 115 practices was 1,586 in March 2010 (78). Numbers of carers registered with GP practices across the city varies considerably, and can range from 10 in one practice to 127 in another. This is not a true reflection of actual numbers of patients that are carers and is likely to be an *underestimation* of the number of carers within a practice population.

Carers UK and the Royal College of Physicians estimate that approximately 10% of a Practice's registered population will be adult and young carers (79). For Sheffield this could mean that potentially there are 55,647 carers, including young carers, (10%) of the registered practice population (556,475) that have informal caring responsibilities.

However it is likely that a large proportion of carers are either not self identifying and as a consequence are not systematically recorded on some Practice registers. This is likely to mean there is a proportion of unmet need within Practices and that carers needs across all Consortia and in particular in the Central and HASC consortia are not being fully met. Identifying informal carers is challenging for practices, as this is dependent, to some extent, on carers making themselves known to their GP, practice nurse or receptionist. Self recognition and acknowledgment of the caring role can take up to two years before an individual asks for support (80). It may be at this point, or some time after, that carers *then* talk to or ask their GP or practice nurse for support.

**Table 5 Table showing Practice Numbers of Young and Adult Carers Registered by Consortia and Expected Numbers of Carers Based on 10% of Practice Population March 2010.**

Practice Based Consortium	Consortia Popn 09/03/10	Actual Carers Registered in Practices	Estimated 10% Consortia Popn	Difference Observed	Actual Carers Registered as % of practice population
Non Consortia	11,664	29	1,166	-1,137	0.25%
Central PBC	131,568	592	13,157	-12,565	0.45%
West PBC	115,087	238	11,509	-11,271	0.21%
HASC PBC	169,383	688	16,938	-16,250	0.41%
North PBC	128,773	722	12,877	-12,155	0.56%
<b>TOTAL</b>	<b>556,475</b>	<b>2,269</b>	<b>55,647</b>	<b>-55,378</b>	<b>1.88%</b>

Again the figures show that there are higher numbers of carers *currently* on practice registers within the North consortia. However there are higher numbers of carers registered in Hallam and South consortia. From the table it can be seen that the highest number of *estimated* carers are again in the North (12,877) and Hallam and South Consortia practices (16,938). This indicates there may be a significant proportion of *unidentified* carers within practices in the West Consortia practices.

## **6.6. Incidence of Informal Caring in Sheffield**

### **6.6.1. Estimated Incidence**

There are few studies on the incidence of caring in the UK. Again, the only robust source of data that incidence can be calculated on, is the 2001 Census (81). Based on calculated prevalence from the 2001 Census approximately 600 adult and young people *move into* a caring role each year in Sheffield. This is assuming that the level of caring prevalence remains static. Numbers are unknown on 'lifetime' carers, such as those looking after children with a permanent disability. As mentioned previously numbers of former carers, or people who are no longer in a caring role are also unknown. It is likely that levels of informal caring fluctuate in Sheffield and that people who have caring responsibilities will move in and out of caring annually or periodically due to the needs of family or friends.

## **6.7. Age and Onset of Informal Caring in Sheffield**

### **6.7.1. Adult Carers**

Evidence from the 2001 Census, and the Sheffield SHAIPS data (82, 83) shows that caring increases with age, reaching a peak in the 40-60 age group, '45% of all carers were aged 45-64'. The largest cohort of informal carers in Sheffield are adult carers of working age in the 35-64 year age group. Unsurprisingly older people are also more likely to experience ill health themselves and combined with a caring role, which in turn can prolong or exacerbate ill health (84).

**Table 7 Table taken from SHAIPS 2002 showing Prevalence of Informal Caring in the 45-54 Age Group**

Age/Sex		Actual% of respondents caring for at least 1 hour per week	Actual% of respondents caring for at least 50 hours per week
35-44	Male	9.3%	2.0%
	Female	13.9%	2.8%
45-54	Male	12.0%	1.9%
	Female	19.1%	3.7%
65-74	Male	12.8%	5.5%
	Female	10.1%	4.0%

As Sheffield's population of older people over 65 years old is predicted to increase to 91,800 by 2016 (85) it would seem likely that, accordingly, older carers within these older age groups will have increased. This presents a significant challenge to health and social care services in the next few years, making it crucial to continue to support informal carers.

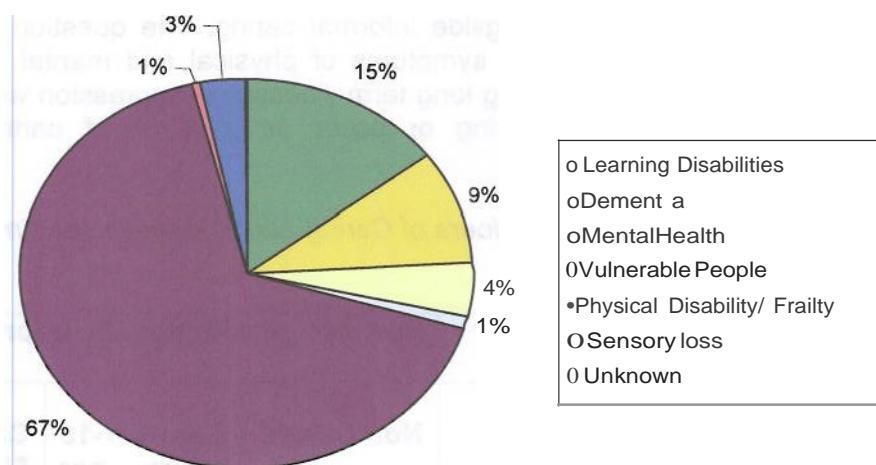
#### 6.7.2. Young Carers under 18years old

The average age of identified young carers in Sheffield is twelve years old (86) and this reflects the national profile of young carers. However, it is difficult to establish at which age the onset of informal caring is for young carers in the city. National evidence states that children as young as six years old are undertaking some form of caring for parents or siblings (87). Young carers may be particularly anxious about going against family wishes to ask for support that may involve outside organisations (88). This is particularly pertinent to young carers who may be looking after family members with substance misuse or mental health issues (89). In Sheffield, the majority of young carers remain a hidden community, with the full extent of the age spectrum of young carers in the city unknown.

#### 6.7.3. Adult Carers known to Statutory Services 2011

*Fig 8 Pie Chart showing Specific Conditions and Corresponding Numbers of Carers Based on CareFirst Data, Sheffield City Council/2011.*

Numbers of Known Carers in Service Areas 18+years 2011\*



\* Figures based on Sheffield City Council CareFirst database 4,820 carers Feb 2011.

It is evident that the majority of known carers, whose relatives are receiving support, from Sheffield City Council are looking after someone with a physical disability and/or frailty. The second largest group are those looking after someone with a learning disability. However, some of the carers in the sample have 'multiple' caring roles and are looking after one person with two or more conditions or a number of people with varying conditions. As carer numbers in the sample are so small (under 5000) and not an accurate picture of 'multiple' caring roles, it is not possible to apply this to the estimated overall carer population in Sheffield to calculate groups of carers who are looking after someone with a particular condition or disability.

However, previously it has been estimated there are potentially 25,000 carers in Sheffield looking after someone with a mental health condition (90) and 6,000 carers looking after someone with dementia (91).

## 6.8. Hours of Caring by Informal Carers in Sheffield

### 6.8.1. Local Data

The Sheffield Health and Illness Prevalence Survey (SHAIPS) 2002 (92) is the most recent and comprehensive study of informal carers in Sheffield and outlines how caring impacts on physical and mental health. The SHAIPS question used was identical to the 2001 Census question and specifically looked at hours of caring, caring duration and whether this affected carer health and wellbeing (93).

Local data from the SHAIPS Survey in 2002 (94) outlines an *increase in the likelihood* of experiencing a long term limiting illness or depression with an increase in hours of caring. Analysis within the SHAIPS report also highlights '*those caring for at least 50hrs per week reported notably higher levels of either limiting long term illness or borderline depression, than other carers or non carers*' (95).

Those providing longer term caring were also more likely to experience a limiting long term illness; *for both men and women, those reporting extended periods of caring reported higher levels of limiting long term illness*'. (96). A Carers UK report included Sheffield as one of five cities, as having the greatest proportion of full time carers (caring over 50 hours per week) self reporting 'ill health' (97).

It is not established whether those people with prolonged and heavy hours of caring had symptoms of illness or depression *before* they were in a caring role. Similarly to the practice Consortia data, SHAIPS data suggests that symptoms of carer physical and mental ill health are *more likely* to be present alongside informal caring. The question of whether informal caring exacerbates and prolongs symptoms of physical and mental ill health in carers is unconfirmed. Also, whether limiting long term illness and depression were present in respondents *before* the onset of caring or occur as a *result* of caring remains unconfirmed.

**Table 9** Table taken from SHAIPS 2002 showing Hours of Caring and Prevalence of Limiting Long Term Illness and Depression

	Percentage with limiting long term illness		Percentage with definite depression			
Age	Non-Carers	Carers 1-19 hours per week	Carers over 50 hours per week	Non Carers	Carers 1-19 hours per week	Carers over 50 hours per week
25-34	10%	13%	25%	5%	12%	6%
35-44	14%	20%	24%	5%	5%	13%
45-54	24%	20%	30%	7%	6%	16%
55-64	35%	36%	51%	9%	7%	12%
65-74	49%	56%	57%	7%	6%	6%
75+	66%	67%	61%	15%	18%	14%

## 6.9. National and Local Evidence on Risks to Health Associated with Caring

### 6.9.1. Positive Factors

Both adult and young carers report that informal caring can have advantages and disadvantages on their health and wellbeing (98, 99, 100).

Many carers report that they want to continue to care for their loved ones and that their caring role is a valued and important part of their life (101). National evidence suggests that informal caring is a positive factor in many communities and in a society where family structures have fragmented, informal caring between family members and neighbours maintains intimate and social bonds.

Informal caring encourages social capital and strengthens community and family relationships (102). Caring can strengthen family ties and there is often a strong bond between the carer and 'cared for' person (103).

For young carers, caring can build practical and personal skills, foster independence and maturity (104, 105). However, adults and children may not recognise their role as a carer and consequently do not ask for support from agencies and professionals. Young carers may accept their caring responsibilities as a natural part of family life. Adult and young carers may not make others aware of what they are doing due to stigma or embarrassment and forgo much needed support as a result.

#### **6.9.2. Health and Health Inequalities**

Evidence suggest that caring brings with it a numbers of stressors which can include physical strain, such as backache, high blood pressure and lack of sleep (106, 107). National evidence also suggests that carers of all ages, in comparison to non carers, are a group at greater risk of experiencing ill health as part of wider inequalities overall, such as relatively high rates of social and economic disadvantage (108, 109). In particular, children and young people who have caring responsibilities are at an increased risk of experiencing disadvantage *earlier on* in their life course in the form of limited social, educational and career opportunities (110).

The act of caring in itself does not mean that a person will be inevitably affected by mental or physical ill health (111). However, the social and economic circumstances of carers and the support networks they can call upon would appear to be a contributory factor in whether they will experience ill health. Evidence suggests that pre-existing life circumstances (education, health, personal wealth and 'social capital') are more influential on whether caring affects a person negatively (112). However, research highlights a strong link between being *more likely* to experience ill health, poverty and social exclusion as one of the negative affects of caring (113, 114).

Furthermore some carers can experience health inequalities that are also associated with gender, ethnicity or sexuality, for example gay carers, or same sex couples (115). In this way caregiving could be seen as '*an underlying social determinant in the creation of health inequalities*' (116). In particular, informal carers who have heavy, periodically long term or lifetime caring responsibilities experience limited or depleted opportunities to access employment, education or pursue personal interests (117).

### **6.10. Caring and Mental Health**

#### **6.10.1. Carer Mental Health**

The increased risk of experiencing adverse physical and psychological ill health as a possible result of informal caring is highlighted in UK and American research (118, 119, 120). In particular, the links between long term and long hours of caring (more than 50hrs of care per week) and ill health are documented in research by the University of York (121) and by Carers UK (122).

Carers mental health can be negatively affected by symptoms of anxiety, depression and social dysfunction (123) and again research highlights that suffering mental ill health is much more likely for informal carers '*carers themselves experience high levels of mental health problems and may need support to maintain their own mental health*' (124). In particular those looking after family and friends with mental heath conditions can find their own mental health suffering as a result (125). Social and emotional effects can also include; social isolation and reduced opportunities to see friends or pursue personal interests outside of the caring role (126).

Evidence highlights that mental ill health (anxiety and depression) are *more likely* to be present *alongside* informal caring. It is *likely* that informal caring on a continuing basis increases the chance of carers experiencing mental ill health and possibly prolongs periods of mental ill health if people had symptoms of this prior to caring (127, 128).

### **6.10.2. Long Term Intense Caring**

A number of national and international studies suggest that prolonged periods and long hours of caring per week may have a detrimental effect on mental health (129, 130, 131) and that over time continuing poor mental health in turn can lead to physical illness, such as back strain or hypertension (132). Estimating the numbers of informal carers in Sheffield, who experience mental health issues is complex. It's likely that a large proportion of carers, at some point in their caring role, have experienced stress, anxiety or worry.

The SHAIPS data highlighted that locally Sheffield carers who were caring for at least 50 hours per week *self reported* long term limiting illness and depression (133). This could suggest an association between an *increase* in ill health, physical or mental, and an *increase* in hours of informal caring. People providing substantial caring and looking after someone for more than 50 hrs per week reported having 'poor health'.

An Office of National Statistics survey (ONS) from 2002 presented the prevalence rates amongst carers, aged 16 and over, of common mental disorders. These covered symptoms of worry, depression, and anxiety, as well as others. To calculate prevalence rates, a score of 12 or above in the Clinical Interview Schedule (CIS-R) indicated mental health issues.

From this 21% of female carers and 12% of male carers, aged over 16 years, from a total of 1350 carers in the ONS study had a score of 12 and above indicating symptoms of mental health distress. Applied to the estimated carer population in Sheffield of 61,874 for 2011, of adult carers (20 – 65+ years) this could mean that 7, 194 female carers and 3,313 male carers have *some form* of common mental health condition, as an impact of caring.

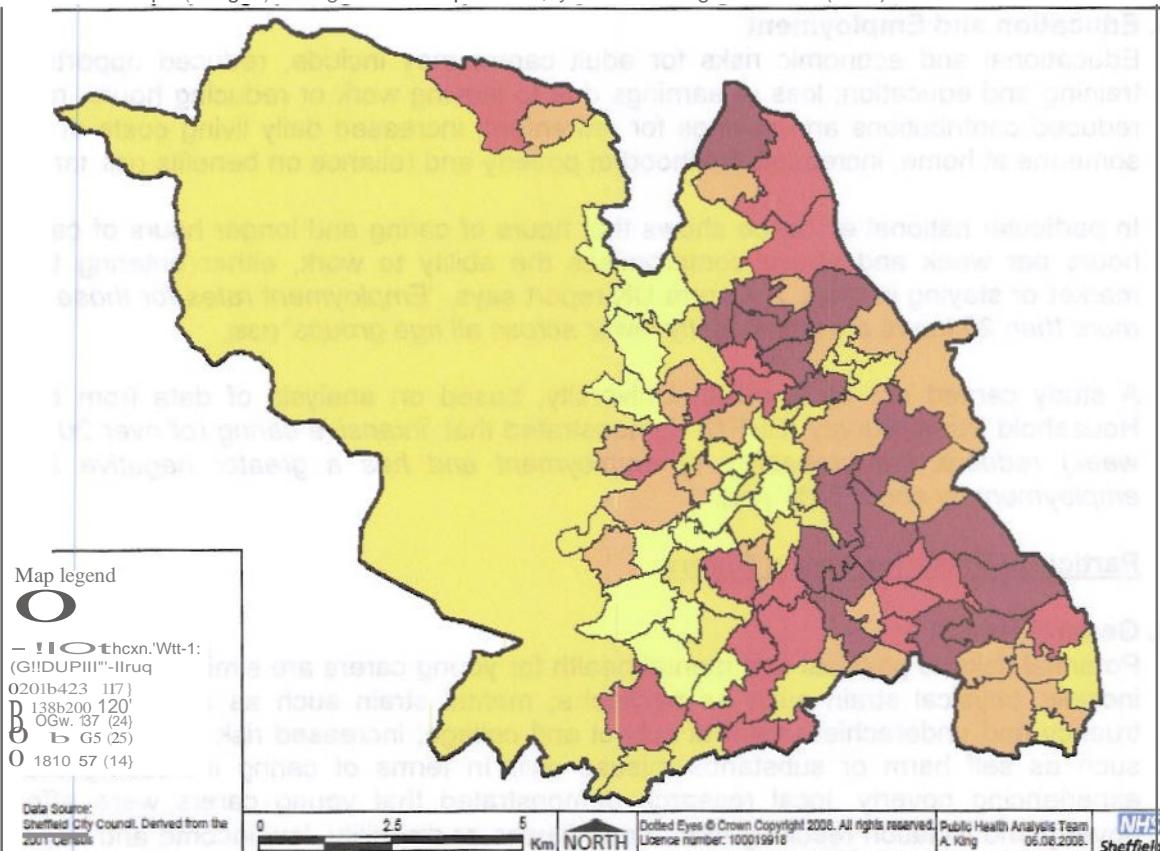
Again a number of international, national and local studies have indicated that the *likelihood* of experiencing mental distress increases if people are caring for *more* than 20 hours per week, are *living* with the cared for person and are in an *intense* caring role (134). Using the ONS data for Sheffield, this could mean that out of 61,874 carers aged 20 - 65+years, 12,225 (35.7 %) of the female carers and 9,334 (33.8 %) of the male carers, due to the level of their caring role (20+hours per week) may have an *increased risk* of having a common mental health condition.

More recently, the British Household Panel Survey (BHPS) (135) from 2008 showed that 35% out of 422 carers, who were caring for someone 20+ hours per week, had a General Health Questionnaire (GHQ) score of 4 and above, indicating some degree of anxiety and depression. Again applied to 61, 874 carers in Sheffield, age 20-65+years, that are caring for 20+hours per week, 7,545 carers (35%) could be experiencing mental ill health as a result of longer hours of caring.

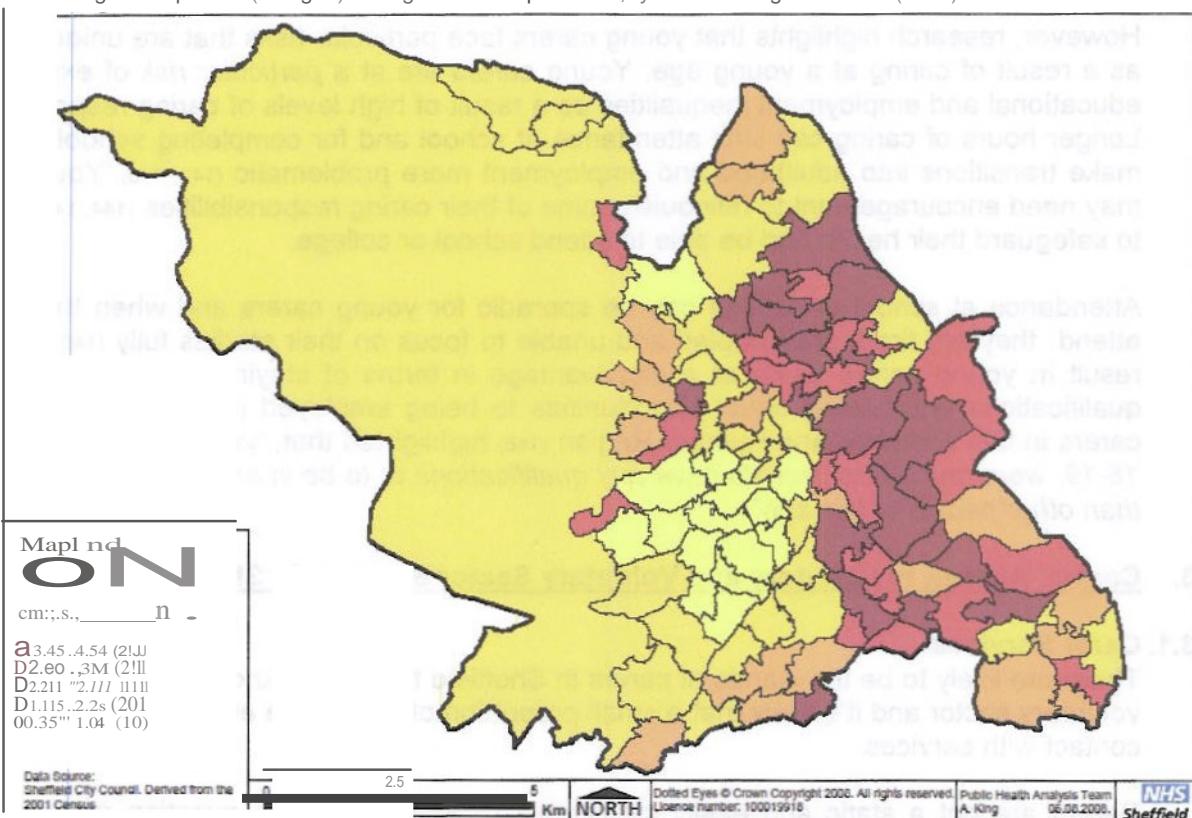
### 6.10.3. Carers in Sheffield providing Longer Hours of Caring.

*Fig 10 Map showing Geographical Distribution of Carers in Sheffield based on 2001 Census data and applied to 2008 Population Estimates of Sheffield.*

Number of People (All Ages) Caring 50+ Hours per Week, by Sheffield Neighbourhood (2001)



Percentage of Population (All Ages) Caring 50+ Hours per Week, by Sheffield Neighbourhood (2001)



The map shows that carers undertaking longer hours of caring of over 50 hours per week are concentrated in the North and Central consortium.

## 6.11. Wider Impacts of Caring

### 6.11.1. Education and Employment

Educational and economic risks for adult carers may include, reduced opportunities for training and education; loss of earnings due to leaving work or reducing hours, resulting in reduced contributions and savings for retirement; increased daily living costs of caring for someone at home; increased likelihood of poverty and reliance on benefits (136, 137).

In particular national evidence shows that hours of caring and longer hours of caring of 20 hours per week and above compromises the ability to work, either entering the labour market or staying in work. A Carers UK report says, '*Employment rates for those caring for more than 20 hours are significantly lower across all age groups*' (138).

A study carried out by Sheffield University , based on analysis of data from the British Household Panel Survey (BHPS) demonstrated that '*intensive caring (of over 20 hours per week) reduces the probability of employment and has a greater negative impact on employment by about 20%*' (139).

## 6.12. Particular Risks for Young Carers

### 6.12.1. General Health

Potential risks to physical and mental health for young carers are similar for adults and can include; physical strain such as backache; mental strain such as stress and tiredness; truancy and underachievement at school and college; increased risk of coping behaviours such as self harm or substance misuse (140). In terms of caring increasing the risk of experiencing poverty, local research demonstrated that young carers were affected by poverty and isolation resulting from family illness or disability, low income and dependence on benefits. This is coupled with stress and worry of having a sick or disabled parent (141).

### 6.12.2. Education

However, research highlights that young carers face particular risks that are unique to them as a result of caring at a young age. Young carers are at a *particular risk* of experiencing educational and employment inequalities as a result of high levels of caring responsibilities. Longer hours of caring can limit attendance at school and for completing school work and make transitions into adulthood and employment more problematic (142, 143). Young carers may need encouragement to relinquish some of their caring responsibilities (144, 145) in order to safeguard their health and be able to attend school or college.

Attendance at school or college can be sporadic for young carers and when they do attend they are tired, preoccupied and unable to focus on their studies fully (146). This can result in young carers being at a disadvantage in terms of staying in education to gain qualifications and having equal opportunities to being employed (147). A profile of young carers in the Yorkshire and Humber Region (148) highlighted that; '*young adult carers, aged 16-19, were much less likely to have any qualifications or to be in employment or education than other people of this age*'.

## 6.13. Carers' Access to Statutory and Voluntary Sector Services in Sheffield

### 6.13.1. Carer Services

There are likely to be thousands of carers in Sheffield that are unknown to the statutory and voluntary sector and it's likely that a small proportion of carers are aware of, accessing or in contact with services.

Carers are not a static and easily identifiable population, so the question remains as to whether they are excluded from and experience disadvantage in accessing services and in

particular health and social care services (149). It is therefore important to commission services that are meeting the needs of hidden carers and those that are most in need.

Evidence suggests that carers often forgo maintaining their own health and focus on the needs of the person they care for (150). Often the carer's deep sense of responsibility for the person they look after prevents them from accessing services. In this way the caring role takes precedence over many aspects of their lives and can limit personal autonomy to address their own health issues (151).

For the majority of carers supported by the voluntary sector, this support is intensive, and includes taking forward carer support plans, carer counselling, advocacy, group or one to one work. A smaller proportion of service delivery to carers is of 'light' support such as signposting to other services and giving specific or general advice.

## 7. Interventions for Adult and Young Carers

The following section outlines: **P23** the importance of carer support and current spend on carer support in Sheffield. **P24-27** Table 11 outlines good practice in carer support nationally and locally and the evidence base for this. **P27-30** Good practice in carer support in Sheffield across a variety of interventions is examined. **P30-32** Emerging evidence on Return On Investment (ROI) and Social Return on Investment (SROI) in adult and young carer support is then discussed. **P32-33** Finally recommendations are made for commissioning carer interventions in Sheffield based on available evidence.

### 7.1. Spend on Carer Support

The current 2010/2011 contractual value of carer support by NHS Sheffield and Sheffield City Council is approximately £958k, which is used to commission a range of interventions for adult and young carers, such as emotional support, social activities, respite, financial and practical advice. Investing in carers services is regarded as important to the social and financial economy in Sheffield (152). Supporting adult and young carers contributes towards reducing worklessness, maintaining carer health and wellbeing and fostering social capital. In particular, investing in support for young carers is regarded by statutory services, as a positive intervention in helping to raise young peoples' aspirations and improving the emotional and physical health of children and young people (153, 154).

### 7.2 Carer Interventions in Table 11

Evidence for and effectiveness of carer interventions are summarised in Table 11. Interventions are prioritised according to their effectiveness in supporting carers. Table 11 summarises carer interventions based on the weight of local evidence and recently published national evidence on the effectiveness of carer interventions over a relatively long period of time (up to two years). It is considered that the most effective adult and young carer interventions are: primary care support for adult and young carers, planned breaks for carers, adult and young carer support groups and carer education programmes.

There is little national evidence on comparing the cost effectiveness of similar carer interventions, however, Table 11 highlights differences in the cost of providing these interventions nationally and locally. It can be seen that Sheffield interventions compare favourably in terms of financial investment. For example, the cost of providing carer breaks is £300 in comparison to £600 as a minimum cost of a break in one demonstrator pilot site.

**Table 11 Table showing National and Local Good Practice and Evidence for Carer Interventions**

National Evidence Adult Carers					
Interventions in Order of Priority	Description of Intervention	Cost/No Of Beneficiaries	Financial Return on Investment ROI and /or Social Return on Investment SROI	Evidence Hierarchy and Type	Source
<b>Priorit£1</b> Primary Care Support Pilot (25 sites) Site 1	<p>Carers Health Checks Sites (includes Physical Health; Mental Well being; Current Medication; Clinical checks on Blood Pressure; Blood Sugar and Cholesterol).</p> <p>NHS Support Carer Sites (includes Advocacy; Befriending Schemes; Peer Support activities; Referral to Carer Support; Carers Assessments ; Carer Recognition Workers).</p>	<p>Costs per carer range from £336- £2,336 per health check.</p> <p><b>Average cost per carer £1,103.</b></p> <p>Total 5,441 carers received health checks over two years</p> <p>Costs per carer range from £1,483- £171 for enhanced NHS support.</p> <p><b>Average cost per carer £958.</b></p> <p>Total 7,557 carers taken up support over two years.</p>	<p>No evidence for direct Financial ROI</p> <p>Some qualitative evidence on mental and physical health benefits for carers.</p>	<p>Level 4 Evaluation Report of Department of Health funded national pilot sites.</p> <p>Evidence from non experimental studies from more than one centre or research group.</p>	<p>National Carers Strategy Demonstrator Sites Evidence Report University of leeds November 2011</p>
<b>Priorit£1</b> Primary Care Support Pilot Site 2	Increase support to carers in GP surgeries (includes Health Checks; Advice & Support Workers; Counselling; Occupational Health Assessments).	<p>Cost not available</p> <p>793 carers responded within a five month period.</p>	<p>No evidence for direct Financial ROI</p> <p>Some qualitative evidence on mental and physical health benefits for carers.</p>	<p>Level 4 Evaluation Report of small sample empirical study.</p>	<p>GP Carers Project South West Devon University of Plymouth 2009.</p>
<b>Priorit£2</b> Planned Breaks	Carer Break Sites (Carer takes a planned break ranging from Respite Care; Sitting Service; Weekend Away; Regular time set aside).	<p>Costs per carer range from £6000 - £603.</p> <p><b>Average cost per carer £2076 of planned break.</b></p> <p>Proportion of duration and type of break not available.</p>	<p>No evidence for direct Financial ROI</p> <p>Some qualitative evidence of immediate short term mental health benefits for carer.</p>	<p>Level 4 Evaluation Report of Department of Health funded national pilot sites.</p> <p>Level 3 Systematic Review of efficacy of carer interventions.</p>	<p>National Carers Demonstrator Sites Evidence Report University of Leeds November 2011</p> <p>Interventions for Carers in the UK PRTC and University of Nottingham 2009.</p>

<b>Priori 3</b> Peer Support Groups	Facilitated and self run carer support groups	Not available*	No evidence for direct Financial ROI  Some qualitative evidence on mental, emotional and social benefits for carers.	Level4 Evaluation Report of investment in Carers Centres  Level3 Systematic Review of efficacy of carer interventions.	Investment in Carers Centres Report PRTC and Baker Tilly 2011  Interventions for Carers In The UK PRTC and University of Nottingham 2009.
<b>Priority 4</b> Carer Education Programmes	Carer attends a specific educational programme (Information on illness/disability/dealing with behaviour/coping strategies/planning for the future).	£400 per participant average cost at 2.5hours weekly for 6 weeks.	Some qualitative evidence of practical and emotional benefits for carers.  Some evidence for direct Financial ROI on self management programmes of £1800 to NHS services (GP consultations/A&E attendances/outpatients visits/physiotherapy use) per person per year. SROI calculated as £16.53 for every £1 invested.	Level3 Systematic Review of efficacy of carer interventions.  Level4 Report of evidence review of efficacy of self management courses	Interventions for Carers in the UK PRTC and University of Nottingham 2009.  Self Care Reduces cost and Improves Health Expert Patient Programme Feb 2010.
<b>Local Evidence Adult Carers</b>					
<b>Priority 1</b> Primary Care Support within citywide consortia	National Quality Outcome Framework requirements as a minimum practices to hold a written policy and a mechanism to refer carers onto social services and support. (Additional support includes flexible appointments , reviews of long term carers and annual carer health checks).	Within GP Contract Payment of QOF points to practices approx £375 per annum.	No evidence for direct Financial ROI.  Some anecdotal evidence that primary care recognition has emotional, physical and practical benefits for carers.	Leve16 NHSS QOF Reviews in GP surgeries  Level6 Citywide Carers Strategy Consultation documents	QOF Review Carers Policies Documents  Citywide Carers Strategy Consultation 2010
<b>Priority 2</b> Planned Breaks	Carers can access funding to purchase a flexible and planned break.	£300 for 227 carer breaks per annum	No evidence for direct Financial ROI.  Some qualitative evidence of the mental and physical benefits for carers.	Level6 Service Review  Level6 Citywide Carers Strategy Consultation documents  Level6 Service data Case Studies	Sheffield City Council2010  Citywide Carers Strategy Consultation 2010  Voluntary Sector Service Data/Quarterly Monitoring
<b>Priori 3</b> Peer Support	Facilitated and organised carer	Approx £1000-1500	No evidence for direct Financial ROI.	Level6 Citywide	Citywide Carers

Groups	support groups.	<b>running costs per group</b>		Carers Strategy Consultation documents	Strategy Consultation 2010
	80-100 carers across 8 groups.	Some qualitative evidence of the mental and social benefits for carers.		LevelS Service data Case Studies	Voluntary Sector Service Data Quarterly Monitoring.
<b>Priorit 4</b> Carer Education Programmes	Facilitated education programmes for carers and parent carers.	<b>£1000 for 6 weeks course 10 participants at £100 per carer.</b>	No evidence for direct Financial ROI.  Some qualitative evidence of the practical, emotional and mental benefits for carers.	Level S Evaluation Report Non Experimental Study  Level 1 Randomised Controlled Trial  LevelS NHSS Programme Feedback	Expert Patients Programme Self Care Reduces Costs February 2010*  Effectiveness of Self Care Support Programme October 200S*  Feedback Data 2010
<b>National Evidence Young Carers</b>					
<b>Priori 1</b> Young Carer Support	Interventions could include Group Activities; Counselling; Advocacy, and Training.	<b>£2,500 per capita.</b>	Modelled Financial ROI of young carers interventions is £5.72 for every £1 invested in support to young carers.  Some qualitative evidence of mental, emotional, physical and social/educational benefits for young carers.	LevelS Evaluation Report Evidence Review	Economic Evaluation of Young Carers Interventions PRTC, Crossroads and University of Manchester 2008
<b>Local Evidence Young Carers</b>					
<b>Priorit 1</b> Young Carer Support	Interventions include; Group Work; Advocacy; Social and Leisure Activities; Information and Advice.	Not available. Approx 90 young carers supported per quarter.	No evidence for direct Financial ROI.  Substantial qualitative evidence of the emotional, social and educational benefits for young carers.	level 5 Evaluation Report Non Experimental Study  LevelS Evaluation Report Non Experimental Study	Meeting Young Carers Needs: An Evaluation of Sheffield Young Carers Project loughborough University 2000  Sheffield Young Carers Project: An Evaluation loughborough University 1998

\*Cost breakdown not available.

\* These two national studies refer to **patients** with a long term condition **not** carers.

### **7.3 Good Practice in Carers Support Interventions in Sheffield**

As Table 11 shows, good practice in carer support is provided in a number of ways, across a variety of settings in the statutory and voluntary sector. Some of the interventions, for example, the carer breaks scheme and peer support groups provide complementary support to statutory services to carers provided by primary care (via the Quality Outcomes Framework) or NHS Sheffield (practical training courses for carers).

In particular the carer breaks scheme and the peer support groups for both adult and young carers help in addressing carers' social, emotional and psychological needs. National and local evidence suggests that without the existence of peer support groups, carers, and in particular young carers' mental health may deteriorate. Carers in Sheffield have highlighted the invaluable support these groups provide for them (155). Young carers express very similar views on how much they value the mutual understanding and friendships these groups provide (156, 157).

Despite the inconclusive and mixed evidence on the effectiveness of a respite break on carer's physical and mental health (158, 159) anecdotal reports from carers in Sheffield place a high value on the carers breaks service, as a chance to take some time back for themselves and 'mentally recharge' (160). Equally, young carers value the annual residential trips that give them the chance to be away from home and the caring situation (161, 162).

The following sections from 7.4 to 7.8 explore the evidence base of carer interventions in Sheffield in greater depth. Much of the local evidence is qualitative, with national evidence reinforcing the effectiveness of local support for carers.

### **7.4 Interventions in Primary Care**

There is good practice nationally (163) and in Sheffield demonstrating that primary care support to carers is effective and can pay dividends for both the carer and possibly for health services. Research has highlighted that informal carers hold their GP and local surgery in high regard and that primary care is often the first point of contact for many carers (164). There are a number of practices in Sheffield that have effective ways of identifying and supporting carers, that are shown in Table 12 (165). National good practice and local good practice demonstrates the key to sustained effective support to carers requires utilising a dedicated staff member within the practice team to promote carers issues (166). For Sheffield, this means that good practice in primary care support could be rolled out, with a requirement to have a dedicated carers champion and to offer annual health checks to carers.

**Table 12 Table showing Sheffield GP Consortia Good Practice in Carer Identification and Support within Practices taken from March 2009 - March 2011 Quality Outcome Framework (QOF) Reviews**

<b>GP Practice</b>	<b>Consortia</b>	<b>Registered Carers</b>	<b>Range of Interventions to Identify and Support Carers</b>
A	North	112	Note on repeat prescriptions to identify carers. Annual health check for carers with practice nurse. Practice leaflet encourages patients to identify themselves as a carer.
8	North	90	Notice board dedicated to information for carers. Annual letter and questionnaire to patients asking them to complete carer referral form. Priority and longer appointments for carers.
C	North	65	Annual searches of patients over 75 yrs with chronic disease to identify carers. Reminder on clinical system to ensure registered carers offered health check.
D	Central	74	Encourage all practice staff to identify and support carers. Long term carers reviewed on an annual basis.
E	West	65	Letter to patients as part of flu vaccination campaign asking if they are a carer/have a carer.

### 7.5 Flexible Planned Breaks Service

The planned breaks service for carers is highly valued by carers who look after individuals with mental health issues, learning disabilities, physical disability, sensory impairment or frailty and dementia. The scheme is funded by the City Council via the Carers Grant and supports some carers who are not in receipt of support from statutory services. In comparison to the costs of providing a break to carers as part of the Demonstrator Sites, the cost of carer breaks in Sheffield is a relatively low cost intervention that can enable carers to continue caring.

The breaks fund is a demand led service which fluctuates throughout the year, with demand being higher in the summer months. Due to an increase in funding (£110K) this financial year has seen an increase in the number of breaks offered and 123 breaks have been awarded between April 2011 and September 2011. Applications for carer breaks are being awarded at an average of 35 breaks per month, with a higher number of carer breaks being offered to an increased number of carers. Based on estimates of current adult carer prevalence of 61,000, 0.3% of carers are accessing a planned break.

In particular, there has been a 25% increase in breaks offered to BME carers over the last year. Research currently being undertaken by Sheffield City Council highlights that '*48% of applying carers are not in receipt of any services and 51% have not had a carers assessment*' (167). This demonstrates that flexible breaks are reaching hidden carers that are outside of mainstream services in Sheffield. Sheffield City Council are collating data from applications using postcode, ethnicity, age and service area to gain a fuller picture of demand for breaks. Carers who apply for breaks are predominantly female (72%) which indicates a higher number of female carers or a degree of inequity for male carers in applying for a break.

A large proportion of referrals are from Adult Care Services (22%) and the voluntary sector (37%). Referrals from health services are significantly lower (10%) which could indicate a need to raise awareness amongst health staff of the breaks scheme. The costs of the breaks scheme is summarised in Table 13.

*Table 13 Table showing Costs of Flexible Breaks Scheme for Carers and Client Service Area*

Flexible Breaks Scheme March 2010-March 2011					
Client Group of Cared for Person	Older People	PDSI*	Mental Health	Learning Disabilities	TOTAL
Number of breaks	66	89	41	31	227
Total Value of Breaks	£19,800	£26,900	£12,300	£9,600	£68,600
Average cost per break	£300	£302	£300	£309	£300
Maximum Value of Breaks @ £500 per break	£33,000	£44,500	£20,500	£15,500	£113,500

\*Physical Disability and Sensory Impairment

### 7.6 Peer Support Groups

Both adult and young carers say that peer support groups offer emotional support, self empowerment and an opportunity for the mutual sharing of problems related to their caring role. A number of carers organisations run carer support groups across the city. Generic carer support groups are run by Sheffield Carers Centre and Sheffield Young Carers Project. In 2011 there are eight support groups for adult carers and six support groups for young carers in Sheffield.

Often the groups provide a forum to resolve issues and members help each other in finding a solution to difficult issues they may be dealing with in their caring role. For the younger carers (8-12

years old) that attend the support groups this provides them with the opportunity to mix with other young carers, and take part in creative activities and play (168).

*'I think the main benefit is that you realise you are not on your own.....you feel such a relief when you walk into that room and realise that other people have the same feelings as you'.* Adult carer Sheffield (169).

The groups also have another function in that they have a collective voice into service development, now formalised through the Sheffield Carers and Young Carers Board. Two of the adult carer support groups and one of the young carer groups have recently started to influence commissioning and work with organisations in raising awareness of carer issues. Evidence from national studies shows that peer groups as well as providing social and emotional support, also facilitate input into and improve relationships with service providers, as they do in Sheffield (170). In this way peer support groups build social capital and self empowerment to carers individually and collectively.

## **7.7 Carer Education Programmes**

Evidence nationally and locally, reports positive outcomes for carers that attend education programmes (171, 112, 173). Although there is evidence that estimates the benefits to health services and the SROI of self management programmes (174) there is no specific quantifiable evidence that demonstrates cost savings to the NHS of carer education programmes. However, it is reasonable to assume these programmes increase carers confidence to manage their role more effectively and possibly reduce or delay their utilisation of health services.

Previously NHS Sheffield has commissioned two carer education programmes, 'Looking After Me' and 'Supporting Parents'. Both programmes ran for 2.5 hours per week for 6 weeks and were based on the underlying principles of the Chronic Disease Self Management Course (CDSMC) (175). They looked at a number of aspects of caring, including dealing with tiredness, communicating with professionals and family, coping with depression and difficult emotions, and planning for the future. Anecdotal feedback from course participants on education programmes in Sheffield report positive outcomes on their mental health and practical skills in relation to caring;

*'Taking far less anti-depressants now.....like a group with solutions, processes and tools'.* Looking After Me Course NHS Sheffield.

The cost of delivering the carer education programmes were minimal with costs reduced by using trained volunteers. Carer education programmes can be seen as a valuable tool as part of an overall support package that enables carers to continue in their role, maintain their mental health and increase their caring knowledge and expertise.

## **7.8 Assistive Technology**

Assistive technology has not been included in the interventions table as it an intervention aimed at service users, *not* carers. It can be used as an element of an overall package of support to carers by helping to provide 'peace of mind'. Assistive technology commissioned by Sheffield City Council ranges from general alarms, fall detectors, bed and chair occupancy sensors and smoke detectors (176).

A simple *estimated* calculation can be made on the cost effectiveness of using assistive technology and the potential savings to be made for the cared for. Sheffield Citywide Care Alarms provide telecare support to approximately 13,000 adults in the city that are frail and vulnerable (177). The basic alarm package is at a cost of £4.67 per week with a nominal fee for additional support. At a relatively low cost this service is an effective intervention that in some instances may delay entry to long term residential care and reduce the costs of length of stay in emergency respite care of the cared for (178).

Nationally the evidence base for assistive technology is still evolving and the evidence base for what works is being looked at by Leeds University (179) and locally by Sheffield University (180).

## **8. Evidence on Return on Investment and Social Return on Investment of Carer Interventions**

### **8.1. Return on Investment**

It is difficult to determine a measurable reduction in the use of health or social care services as a direct result of support to carers. There is no agreed methodology that calculates a ROI resulting from carer support and the possible subsequent avoidance of a hospital admission or a reduction in the use of primary care services.

Until recently, there has been a lack of research on the savings to be made to health services resulting from commissioned carer support (181). Two examples are the Return On Investment (ROI) or the health benefits for a carer of a planned break or the provision of information at the right time. One reason for this difficulty is that carer support is usually multi-faceted with individual carers receiving a combination of multiple interventions (e.g advice, counselling, training, planned break) as part of an overall package. This makes it difficult to attribute the impact of a specific intervention (a planned break) on carer health and the resulting return on investment.

Another common factor that influences whether an intervention is effective for a carer, is the quality of the replacement care for the cared for. If carers are anxious about replacement care, while they have a planned break, any tangible physical or mental health benefits for the carer, are negated.

### **8.2. National Carers Strategy Demonstrator Sites**

Innovative practice in carer interventions has been established as part of the government funded Demonstrator Sites (182). These were established as part of the National Carers Strategy to gather evidence of interventions for carers within primary care. The evaluation report presents early findings on three types of carer interventions: carer breaks, carer health checks and enhanced NHS support to carers.

Although the majority of the demonstrator sites reported overwhelmingly positive feedback from carers on the carer support interventions (183) the report states '*although it is too early to have robust statistical data about improvements in health over time, early evidence for health benefits is emerging*' (184).

The final report of the National Carers Strategy Demonstrator Sites (185) shows anecdotal evidence that carers interventions can prevent admission to hospital or residential care for the carer and the cared for (186). Four sites had reported reduced hospital admissions in their local evaluation reports. Specific numbers from these sites show that out of 77 carers receiving NHS Support 9 of the cared for people had avoided an emergency admission or emergency replacement care. Similarly in one of the Breaks Sites staff had reported that in 90 out of 203 carers supported the need for emergency alternative care for the cared for had been avoided. Potential healthcare costs avoided as outlined in the Report are: £95 for Accident and Emergency attendance; £345 for short hospital inpatient stay; £1,571 for a 24hr inpatient stay (187).

Despite this positive feedback, sites were not able to quantify the cost savings or return on investment in relation to the wider health and social care system (188). Reasons for this difficulty were: isolating the specific impact of Demonstrator Sites funding was difficult or impossible; site targets varied and there was inconsistency in the way outputs were measured; the time period of two years was not long enough to measure the impacts of carer support on the wider health and social care system.

Qualitative data within the report indicates a number of benefits for carers as a result of the interventions. These were: '*carers feeling recognised, valued and supported; ability of carers to take a break; ability to continue in their caring role effectively; recognition of carers as expert partners; and benefits for carer health and wellbeing*' (189).

Findings from one pilot site in East Sussex providing breaks for carers highlighted that breaks had a 'positive impact on the health and wellbeing of carers in many cases' (190). A majority of the carers accessing breaks had significant physical and mental health problems *already*, so the impact of a planned break on their physical health remains unclear.

It was clear the case studies highlighted the benefits to health and social care of early identification of carer health issues, providing carers had the necessary treatment (191). It is likely that these inexpensive carer interventions, such as the health checks and enhanced health support, could reap cost benefits on a longer term basis, providing they are fully embedded within primary care systems. However, this is dependent on the engagement of GPs and the commitment of primary care staff in practices to recognise carers as 'expert partners' in patient care and support them.

### 8.3. Dementia

There is a more substantial evidence base in relation to interventions for carers looking after older people with dementia. Evidence highlights that good quality carer interventions (carer education, counselling and planned breaks with good respite care) can delay the institutionalisation of the person with dementia (192, 193). Similarly, a literature review carried out by the Audit Commission and the London School of Economics (194) on the cost effectiveness of support to carers of older people, highlights that respite care as a carer break, did delay admission to institutional care for some older people (195). The review also highlights that services for the cared for, such as day care, institutional respite care and responsive social work input are cost effective in reducing mental distress and anxiety for carers (196).

### 8.4. Carers Centres National Report

A recent report from the Princess Royal Trust for Carers outlines the Social Return On Investment (SROI) of carer interventions via Carers Centres (197). The report measures the social impact and corresponding economic value of investment in carers interventions within five Carers Centres in the UK. SROI methodology used in the report includes measures such as economic benefit created (impact on carer earning capacity or productivity); costs saved (introducing prevention to save on costs of cure such as carer/or cared for using secondary care) alternative sourcing (one early intervention can replace another more expensive intervention later on).

The main finding of the report was that the five Carers Centres generated economic and social annual gains to society of approximately £73million, set against annual funding of less than £5million cross the five Carers Centres\*. Table 14 shows substantial social returns on investment from four areas of work that were: carer identification; information and advice; learning and development and carer involvement.

*Table 14 Table Showing Overview of Findings for SROI in Five Carers Centres 2011 (Executive Summary Carers Centres Report 2011).*

Summary Total Evaluation of Carers Centre work	Proportion of gains attributed - consensus across five Carers Centres (%)	Total Care Life Course Benefits/gains due to each activity (£000' millions) across five Carers Centres.
Carer identification	14	£10,926m
Information and Planning	38	£27,314m
Learning and Development	13	£9,105m
Carer involvement (including the value of carer time)	10	£7,427m
Other services	13	£9,105m
Premium for holistic approach	13	£9,105m
<b>TOTAL</b>	<b>100</b>	<b>£72,982m</b>

\* Average funding from five year time period.

### 8.5. Interventions for Young Carers

There is national evidence that outlines Return On Investment (ROI) and the Social Return on Investment (SROI) for young carer interventions (198). This research shows the likely benefits that voluntary services can have for young carers that go beyond childhood caring into their adult lives. Interventions for young carers show that for every pound invested in interventions for young carers the saving to the Exchequer is £6.72 (199). The research outlines that the average cost of an intervention per capita is £2,500 (200) and the savings made by delivering young carers interventions .

**Table 15** Table Showing Return on Investment (ROI) for Young Carer Interventions: Economic Evaluation of Young Carers Interventions November 2008.

Avoiding young carer going into local authority care (working with family and statutory services).	£50,574
Improving a young carers schooling (advocacy with school staff and young carers' families).	£47,931
Avoiding teenage parenthood (education and self empowerment work with young carers).	£130,405
Supporting a young carer to undertake appropriate caring (working with families and statutory services).	£7,827
<b>TOTAL INVESTMENT</b>	<b>£236,737</b>

Although the literature review found no local evidence on the cost benefits or Return On Investment (ROI) as a result of direct carer interventions for young carers in Sheffield, it is reasonable to assume that interventions for young carers in Sheffield have an economic ROI. Young carer support has a crucial preventative role in many ways; it helps to raise young people's aspirations, reduce absenteeism at school or college, keep young carers out of local authority care, or prevent a young person from becoming a teenage parent. NHS Sheffield and Sheffield City Council investment in young carers support in Sheffield is an effective preventative measure that can save costs to health and social services in the future.

## 8.6. Recommendations for Commissioning Carer Interventions

Based on the limited evidence base to date, it is suggested that, interventions that work well for adult carers in Sheffield are the signposting and support within primary care, the flexible breaks service, peer support groups and carer education programmes. Carers also report that support and signposting from primary care staff is helpful (201). It is therefore recommended, that flexible breaks and peer support groups need to continue to be commissioned. In terms of statutory support, carer support within primary care needs to be embedded and sustained on a long term basis within GP Clinical Commissioning Consortium and localities.

### 8.6.1. Flexible Breaks Service

It is recommended that flexible breaks for carers continue to be commissioned at the current financial value and administered through the voluntary sector. As self directed support rolls out across adult services in the next couple of years, and is increasingly built into service users packages, the demand for planned breaks from carers may decrease. Based on the last year of figures it is recommended that 300 breaks for carers are commissioned annually. However a clearer picture of the demand for breaks and the geographical uptake of breaks is needed in order to quantify future commissioning.

### 8.6.2. Peer Support Groups

It is recommended that professionally run carer support groups continue to be commissioned through the voluntary sector. There are approximately 80 -100 adult carers that attend 8 support groups based in geographical areas across the city. Provision of support groups covers the majority of areas in the city (South East, Central, North, East and West) with the exception of the South West of the city. Currently it is likely there are a limited number of carers aware of and being able to access a support group.

Increased development work of current and new groups needs to take place to ensure an increased number of hidden carers are reached and former carers within current groups are encouraged to use their skills to mentor and 'buddy' existing carers. The new model of carers support that is being rolled out in 2012 will require that existing support groups become more self sufficient and that new support groups, after a period of professional input and support will be encouraged to become more self sufficient.

### 8.6.3. Carer Education Programmes

It is recommended that carer education programmes are commissioned from the voluntary sector to link into and work within GP Clinical Commissioning Consortium. Tutors could be linked into consortia to deliver training to volunteers who are current or former carers. Participants could be recruited from practice registers. This approach would help to embed carer support within primary

care, strengthen and develop identification of carers and the maintenance of a carers register within practices. This will also strengthen and maintain the need for practices to have a carer policy as part of Quality Outcome Framework (QOF) requirements.

#### 8.6.4. Assistive Technology

It is recommended that the City Council continue to commission assistive technology in some form for service users, as this also provides an element of support to carers.

#### 8.6.5. Young Carers

It is recommended that interventions for young carers continues to be commissioned in its current form through the voluntary sector. It is recommended that funding is continued after 2013 to ensure that fundamental support to young carers in the city can continue to be developed and built on.

#### 8.6.6. Strengthen the Evidence Base

Robust research needs to be commissioned and taken forward in Sheffield to establish a stronger evidence base for the cost effectiveness and Return On Investment (ROI) of commissioned planned carer breaks. This is particularly relevant in view of recommendations from the National Carers Strategy in 2008 that the NHS spend national funding from the Department of Health to commission planned carer breaks. Establishing a conclusive evidence base for carers breaks over the next year would be beneficial regarding future decision making on whether to jointly commission with Sheffield City Council greater numbers of carer breaks using Department of Health funding.

Further research, that is beyond the scope of this health needs assessment, needs to take place to establish the numbers of young carers, black and ethnic carers, male carers and migrant carers in the city. Estimated prevalence for all these groups is very hard to establish and until this is done services cannot be tailored cost effectively to these groups.

### 9. Current Gaps in Identification

#### 9.1. Identification of Carers in Adults and Childrens' Services

Identification of young carers across a number of organisations is a significant gap. Not all children and young peoples' services have procedures in place to identify children and young people who are informal carers. The 2009 Ofsted Report focused on young carers and highlighted that many professionals working in adult services were not aware of young carers. The report stated, '*those working within universal and adult services lacked insight into the impact of a parent's disability on the children and young people in the family*' (202).

Awareness of young carers in schools remains inconsistent (203, 204). The majority of schools have a duty to identify and where possible protect vulnerable pupils by referring them onto professional support. However young carers may not be systematically picked up within this and a robust and systematic method of identifying young carers within schools is needed. Additionally college and university student welfare need to increasingly recognise young adults that are carers and put in the appropriate support. Both adults, childrens and statutory services need to ensure they have a consistent, effective and appropriate method of asking whether a service user, patient or child has caring responsibilities.

In particular there is no robust data on the numbers of young carers under 18 years of age, young adult carers aged 18-24 years, carers from BME communities or migrant carers. All these groups of carers are particularly hard to identify as they often remain 'hidden' within the community for a variety of reasons.

#### 9.2. Evidence on Carers Interventions in Primary Care

Previously primary care support initiatives for carers have been small scale, developmental and funded on a short term basis. Good practice in carer support that has demonstrated effectiveness in meeting the needs of carers needs to be industrialised nationally within primary care.

Currently, with the exception of the quality Outcomes Framework (QOF) indicator that practices have to identify carers, there is no agreed or universal model of carer support in GP practices; '*No single blueprint for how primary care support initiatives operate*' (205). Carers support within primary

care has previously been a largely reactive response. Evidence is demonstrating that a universal and proactive model within primary care is most effective in supporting informal carers.

Staff involved in design and monitoring of the National Carers Strategy Demonstrator Sites work emphasised that in order to gather robust statistical evidence on the effectiveness of the pilots, longer timescales were needed (206). Evaluation of successful carers support interventions in practices demonstrate that long term sustainability is key in how successful interventions are for carers. Factors such as changes in practice staff, the engagement of clinicians, and cooperation of partner organisations and the nature of the intervention are key to supporting carers effectively.

## 10. Equity in Accessing Services

### 10.1. Support Services for Black and Ethnic Carers

Voluntary sector service data (207) suggests that there is a current disparity in take up of services by BME (black, minority and ethnic) carers. Support for carers from a BME background is low within generic voluntary sector services for carers and specific provision for black and ethnic carers is limited to two or three organisations in Sheffield of a small capacity. Local expertise suggests that voluntary sector organisations working with BME communities state there are gaps in services to this section of the community (208, 209).

BME carers may not engage with voluntary or statutory services for various reasons. Myths persist around the assumption that carers from some ethnic groups are part of an 'extended family' of caring and that they have a strong cultural support network that automatically look after family members. Other reasons for lack of identification could be language barriers, a reluctance to self identify and black and ethnic carers lack of knowledge of or perception of carer support services (210). Identification of and provision for, BME carers in Sheffield, needs to increase accordingly to need, so that effective support can be provided for this group.

*Table 17 Table Showing Gender and Ethnic Background of Carers Using Carers services taken from Provider Quarterly Monitoring figures.*

Carers Organisation	Gender Service Users		Ethnic Background Service Users		
	Male	Female	White British	BME	Unknown
A	26%	74%	96%	4%	
B	42%	58%	69%	31%	N/A
C	25%	74%	82%	10%	8%
D	No avail data	No avail data	No avail data	2 contacts per month	N/A
E	No avail data	No avail data	No avail data	No avail data	N/A

### 10.2. Support Services for Male Carers

Voluntary sector data and the Flexible Breaks Service data shows that greater numbers of female carers are accessing support and advice from organisations in Sheffield than male carers. Data from a variety of organisations consistently shows higher numbers of adult and young female carers in touch with and accessing services, than male carers (211). This could be due to a number of reasons, although this indicates there could be a level of unmet need among male carers. Caring has been viewed as a 'female role' and issues of stigma or embarrassment may prevent male carers from seeking help. Male carers may not recognise or acknowledge their role as a carer or they may have a different perspective on the caring relationship with their loved one (212).

Current carer organisations and support interventions such as peer support groups or counselling may not be what male carers want to use or see as helpful to their needs (213). Male carers may want to access support in different ways from women. Research shows that when male carers do access support they do in different ways and are more likely to choose 'formal' support, such as

help with home nursing or housework (214) rather than joining an informal group for peer support. Nationally, a survey of Carers Centres in 2001 found that male carers represented only 25% of membership of carers centre and was as low as 10% in some areas (215).

Evidence highlights the need for change in the prevailing culture that views male carers as 'emasculated' (216,217) and more work needs to done on identifying and supporting male carers.

## **11. Future Commissioning for Carer Support**

### **11.1. Voluntary Sector**

Carers value both statutory and voluntary sector services (218). However, the voluntary sector can 'reach' those carers that may be distrustful of statutory services and establish relationships with carers that are mutually beneficial and equitable. The majority of direct support for 'known' carers in the city is through the voluntary, charity and faith sector. Social support for carers ranges from generic provision by the Carers Centre to tailored provision for specific carer groups such as ROSHNI for BME carers and the Young Carers Project for carers under 18 years of age. Other support is for carers looking after those with specific conditions or illnesses, such as stroke, mental health conditions or drug and alcohol misuse.

Carers in Sheffield value voluntary sector support and in particular young carers 'trust' voluntary sector provision to support them in a non judgemental and confidential way. Young carers may be wary of statutory services, perhaps because of misconceptions of a punitive response from 'official' organisations to family circumstances. In this way the voluntary sector is in a unique position to support carers, irrespective of politics and policy constraints.

New ways of delivering services to carers, in the context of personalisation, is being rolled out in social care services and is imminent in health care. In the near future competitive tendering is likely to be the way that the voluntary sector offers their services to be commissioned. Both commissioners and providers will adopt a 'business model' approach to commissioning and the delivery of services in the future. NHS Sheffield and Sheffield City Council commissioners are working towards developing and implementing a generic model of carer support within the city. This will be across service areas, focussed on common needs of carers, with specific areas in the service to support carers within mental health, physical disability, learning disability and older people. The model will include support to all adult carers including specific groups such as BME carers, male carers and working carers.

### **11.2. Self Directed Support**

The increasing use of self directed support via an individual budget for patients and service users is continuing to be rolled out as a way of accessing services. Sheffield City Council and Sheffield Health and Social Care Trust are in the process of rolling out Self Directed Support in service areas for older people, physical disabilities, long term conditions and mental health services.

Feedback from professionals nationally and locally involved in working with service users and carers is that self directed support has a mixed impact on families and carers. In some cases it has had a positive transformation for the cared for and carer and provided an innovative way of buying in tailored services (219). For other service users and in particular for carers, managing the individual budget has increased paperwork and bureaucracy in relation to care planning and in some cases has resulted in a reduced package of support (220).

The principle of self directed support has had a mixed response from health and social care professionals and carers (221). However for it to be effective in easing carer burden a 'whole family' approach is recommended (222).

Working with carers collaboratively so that their needs are not overlooked is crucial for self directed support to be effective in helping carers as well as service users and patients.

### **11.3. Practice Based Commissioning**

Evidence suggests that contact with primary care services for a majority of adult carers is crucial in accessing support to other services (223). Currently within the Personal Medical Services (PMS) contract, practices are required to '*have a protocol for the identification of carers and a mechanism for referral of carers for social services assessment*' (224). Maintaining this mechanism of identification and support for carers within primary care and within the new GP commissioning arrangements for primary care is crucial. As part of a holistic package of support to carers it is important that awareness of patients with caring responsibilities by primary care staff is not 'lost' in the transition to practice based commissioning. The advent of practice based commissioning provides an opportunity to further embed carer support into primary care services and local commissioning .

Carers UK give the example of GP commissioning consortia commissioning services from local Carers Centres and delivering appropriate services on site at surgeries (225). In Sheffield this could be health checks for carers or a carers support group at the practice. It's likely that from 2013, the NHS Commissioning Board will have the remit to ensure that practices achieve Quality Outcomes Framework (QOF) requirements, that include support for carers.

## **12. Recommendations**

### **12.1. General Recommendations**

All recommendations are to be considered by the Carers and Young Carers Board.

#### Awareness

- Professional understanding of carers and young carers issues is still poor, although improving. Targeted awareness campaigns by Public Health and the City Council need to continue in order to raise awareness and improve identification of carers in a number of statutory services.

#### Identification

- To increase earlier identification of adult and young carers within primary care by embedding a universal and mandatory model of carer support.
- Improve earlier identification of hidden carers across the city that include black and ethnic carers, male and young carers under 18 years of age.
- To increase earlier identification of young carers within schools, adult and children's services.

#### Strategic

- Continue to support young carers via the Carers and Young Carers Board and Young Carers Steering Group to have a strategic voice in influencing and shaping statutory services in the city.
- Accountability and reporting responsibilities in relation to carers to be part of new local strategic partnerships linking into the new Health and Wellbeing Board.

#### Practice

- Local policy within primary care should be adapted to ensure that carers on practice registers are offered an annual health check.
- Build on current good practice by providers and the statutory sector to engage with and extend support to black and ethnic, male and young carers.

## **12.2. Commissioning Recommendations**

### Adult Carers

- Continue to commission the flexible breaks service and peer support groups via the voluntary sector.
- Commission carer education programmes through the voluntary sector with a mandate to link to and work within GP Clinical Commissioning Consortia.

### Young Carers

- Continue to commission young carers support via the voluntary sector after 2013.



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