

## **Bolton's Joint Strategic Needs Assessment**

### **Chapter: Carers**

#### **Introduction**

A carer is someone who supports a relative, partner or friend who cannot manage without this support because of illness, frailty or disability.

An enormous amount of personal and community care is provided by family and friends, and social care and health services should be seen in this context. Estimates of how much the equivalent cost of this informal support would be if carers' input had to be replaced run as high as £87 billion per year, which is nearly as much as total spending on the NHS.

Where services are needed to support people with illnesses, disabilities or addictions, the needs of informal carers should not be neglected, as they are closely linked, and often have a very important bearing on the effectiveness of the interventions for the cared for person.

The pressures on carers are such that that over time the effect on their health and social and financial wellbeing can be significant. Carers need support to continue to care - otherwise care can break down, with considerable cost to the individuals and to the health and care system.

The kinds of support carers may need to maintain their caring role can be wide ranging. Regular breaks, information, emotional support and financial advice are just a few examples. However, only a minority of carers receive support or are in touch with social care services at any given time. Many people, particularly new carers, are looking after their loved ones without recognising themselves as a 'carer'.

It is important to understand as much as possible about the diverse needs of Bolton's carers and about the effects of caring on their own health and wellbeing. Only then can resources be utilised as effectively as possible to target help for carers at times of need, with awareness and recognition of the vital role of carers becoming embedded in service provision and plans.

#### **Key issues and gaps**

As the importance of informal and family support to an effective care system has been more widely acknowledged, there has been a growing emphasis in recent years on the need to provide support to carers. At a national level, carers' strategies have been published in 2001, 2008 and 2010. In 2009 Bolton published its own comprehensive Carer's strategy, 'Supporting Carers in Bolton', key issues and priorities for local carers and introduced a number of service developments. A new strategy for Carers is being published in 2013. Bolton's new local strategy will reflect shifts in national policy priorities relating to carers, and will also respond to what we understand about the diverse and changing needs of carers in different caring situations.

There are carers of all ages. Every year brings new carers, and the majority of these are of working age, balancing caring with other responsibilities, for example, bringing up

children, employment etc. Older carers may be 'propping one another up'. Some carers may be caring for more than one person (a partner and a parent, perhaps). The caring role may be shared across families or broader networks, with complex arrangements making up the fabric of support for an individual. Young carers may be hidden in these family caring arrangements. Some carers are caring at a distance; others may move in with the person they are caring for, relinquishing much of their own independence.

The number of informal carers is expected to increase significantly in future years as the number of older and disabled people increases. The forecast increase in the prevalence of dementia, for example, will result in more people requiring informal care from their families. Currently there is evidence of unmet needs for breaks for carers and difficulties for people when they try to combine employment with their caring responsibilities.

Particular gaps identified include:

- Improved understanding of any specific needs of carers from ethnic minorities and various cultural and community groups
- Improved understanding of the needs of older carers
- Improved understanding of the needs of carers of working age
- Improved understanding of the needs of carers for information or training about different aspects of caring, eg, lifting, nutrition, coping with emotional strain
- Improved understanding of the needs of carers who are providing a lot of emotional support, for example, those caring for people with mental health problems
- Improved understanding of what carers in different situations find to be the most valuable support, from whatever source or sector

Bolton's Carers Strategy 2013 - 2015 emphasises the diversity of carers' situations, and acknowledges the above issues. The strategy's implementation plan states that the limited resources available should support innovative and cost-effective interventions to address the diverse needs of local communities and the different pressures that carers are under.

### **Recommendations for Commissioning**

- Recognise the complex and diverse needs of carers and awareness of the pressures they have and their particular support needs, eg older carers, carers of working age, carers of people suffering mental ill health and carers in BME communities
- Explore options to help prevent the deterioration of health of long term carers and support carers' well-being, enabling them to continue successfully in their caring role
- Explore ways of maximising opportunities for carers to get a break
- Improve information and advice for carers on services, health related information and finance/benefits, to help them make informed choices

- Take action to identify new carers and ensure they are equipped with information and contacts to help them in their caring role
- Consider targeting support for carers in neighbourhoods where there is evidence of a high proportion of people undertaking considerable caring duties and where there is evidence of a greater concentration of health problems

### **Who's at risk and why?**

Carers provide unpaid practical care or emotional support to a partner, child, relative, friend or neighbour, who could not manage without their help. This could be due to age, physical or mental illness, addiction or disability. As noted above, carers can be of any age and may live with or near to the person they are caring for, or they may be providing support from a distance. These different caring situations can present different pressures and risks.

Carers often face greater social deprivation, isolation and ill health and have fewer opportunities to do the things other people may take for granted, such as access to paid employment or education, having time to spend on their own or with friends to do the things that interest them, and in terms of young carers, it can often compromise their education and social life, and their life chances may thus be limited.

Carers UK indicate that some of the ways in which carers are disadvantaged or their own health put at risk are:

- Three out of four carers are worse off financially as a result of caring (72%)
- More than half have given up work to care (54%)
- One in five has to reduce the hours they work (21%)
- On average, carers retire 8 years early, missing out on years of income and pension contributions
- Two out of three working age carers are not in paid work (65%)
- Those caring for 50 hours a week or more are twice as likely to be in poor health as those not caring (21% against 11%)
- Carers providing substantial levels of care are twice as likely to have mental health problems as those providing a lower level of care (27% against 13%);
- Those providing care over a long period of time are at particular risk of poor health and both mental and physical health are likely to deteriorate the longer the carer has been caring.

For carers of working age, the need to balance employment and caring is a considerable pressure. Carers have the right to request flexible working, but there is a very low level of awareness of this provision. 76% of carers were unaware of this in the 2009-2010 Bolton Carers Survey.

### **The level of need in the population**

The Census 2011 showed there were 30,649 people who were looking after another person in Bolton in 2011. This is an increase of more than 2,000 on the previous 2001 Census figures and equates to 11.1% of the population, slightly higher than the national average of 10.3%.

The Census figures report that 18,187 Bolton people (59.3% of local carers) provided 1 to 19 hours unpaid care per week, 4,525 people (14.8% of local carers) provided 20-49 hours unpaid care per week and 7,937 people (25.9% of local carers) carers provided 50+ hours unpaid care per week. A larger % of carers in Bolton provide care for 50 hours per week or more compared with the national profile of carers. (25.9% compared with 23.4% nationally).

### **What do carers do?**

The amount and type of care that carers provide varies considerably. A carer might provide a few hours of care a week, perhaps shopping for a friend or relative, or they may care around the clock. Providing care can range from helping with household tasks on a regular basis to providing continuous care.

The 2012 statutory survey of carers in contact with Adult Social Care in Bolton found that carers were providing support as follows:

- 93% provide practical help, such as preparing meals, doing housework or shopping.
- 59% provide personal care, such as help with bathing, feeding and going to the toilet.
- 53% provide physical help, such as getting in and out of bed or up and down stairs.
- 66% administer medication.
- 88% help with financial matters and other correspondence· 81% give emotional support.

According to the 2010 Bolton Health and Wellbeing Survey, carers in Bolton provided care to people with the following types of illness or disabilities (multiple answers were possible):

- Long term illness 38%
- Physical disability 43%
- Loss of sight 10%
- Loss of hearing 14%
- Learning disability 12%
- Mental health problems 17%
- Dementia (incl. Alzheimer's) 12%
- Other problems of age 31%
- Other 14%

Compared to the findings from the previous Bolton Health Survey in 2007, the most significant change in the kind of conditions or problems that carers were providing people with support for was a jump from 13% to 17% of those supporting people with mental health problems.

The Bolton Health Survey in 2007 found that 85% of carers care for just one person, 11% of them for two people, with the remainder caring for three or more people. Two thirds of carers lived in the same home as the person who they cared for. The third who do not will have the different pressures of caring from a distance, which for some could be a significant travelling distance, and responding to problems and trying to balance caring with other family and work responsibilities,

Almost half (47%) of carers in Bolton in 2001 were aged 45-64 years with 1 in 5 of all

people (21%) in this age group providing some informal care (Information from the 2011 Census will be available later on in 2013). The 2001 Census and the recent Bolton Health Surveys both found that women are more likely to be carers than men, particularly in the 18-64 age category. Women are more likely to give up work in order to care.

A 2009 survey of carers in contact with Adult Social Care (more likely to be providing care for 50+ hours per week) indicated that 22% of those of working age were unable to work because of their caring responsibilities. 9.5% of carers that were working did not feel supported by their employer to combine work and caring. Half of all respondents indicated they had a long term illness or disability themselves. Although the majority of carers known to Adult Social Care appeared to be coping reasonably well:

- 13% assessed their overall quality of life as bad;
- 12% were unable to spend any time doing things they value or enjoy;
- 14% felt they do not have any space or time to be themselves;
- 7% have no control over their daily life;
- 10% feel they are neglecting themselves;
- 9% have little social contact with people and feel socially isolated;
- 10% had developed a health condition as a result of caring over the last 12 months and 13% said it had made an existing condition worse;
- 7% felt caring had caused them a lot of financial difficulty over the last 12 months.

More up to date information will be available in Spring 2013 from a similar Carers Survey carried out in 2012.

The 2001 Census indicated there were then 872 young carers aged 5 to 17 and a further 332 aged 18 to 19 years in Bolton in 2001.

Data from the 2001 Census shows that the peak age for caring is 50 to 59. The number of carers over the age of 65 is increasing more rapidly than the general carer population. Research by Carers UK and the University of Leeds (Carers UK (2011) Valuing Carers) has indicated that whilst the total number of carers increased by 9% from 2001 to 2011, the number of carers over 65 increased by 15% over this period.

The Bolton Health and Wellbeing Survey 2010 found that carers in Bolton show a pronounced vulnerability to mental health inequalities. A significantly higher proportion of carers compared to non-carers reported that they had suffered with depression in the previous year. Carers also have a significantly higher standardised rate for the GHQ12 questions, which include reporting 'feeling unhappy and depressed', 'losing sleep over worry', 'feeling constantly under strain' and can signal possible mental health problems,.

The Survey also found that, carers have significantly higher prevalence rates of suffering recurrent or constant backache. A significantly higher proportion of carers report having a long term health problem or disability compared to non-carers.

A higher proportion of carers report being unable to afford to heat their home adequately, which is a concern as they and those they care for are likely to be in the home for most or all of the time.

National research has found that one in five carers report that their health suffers as a direct result of caring (Carers UK, 2008), as personal health needs are often neglected when faced with the priority of caring for somebody else. This particularly highlights how without proper training carers are especially prone to back problems. Financial difficulties are typical for carers and the link between health and deprivation is manifest.

### **Current services in relation to need**

The 2009-12 Carers Strategy highlighted the following priorities for carers in Bolton:

- Improved recognition for carers
- Strengthening the voice of carers
- Information and advice for carers, including entitlements and benefits;
- access to emotional support for carers, emergency support and training to support them in their role
- support for carers to maintain their health and wellbeing and access to employment learning and leisure opportunities
- Regular breaks for carers

The 2009 Strategy's Action Plan responded to these priorities in a number of ways, including:

- A publicity campaign reached out to people in caring roles to make contact with agencies and receive information
- Training in carer awareness was put in place for health and social care professionals
- Local carers were able to take part in a 'Caring with Confidence' training programme
- A Carers Resource Centre was set up, bringing a number of key carers' groups together in one location
- A range of services are provided by Adult Social Care including day care, which enables carers to get a break, and respite in care homes
- One-off direct payments of £75 from Adult Services are paid to new carers who have had a Carers Assessment to enable them to have a break of their choice
- New assessment processes introduced as part of 'self-directed support' in Adult Social Care have resulted in a greater number of carers having an assessment, However, these only represent carers of people with eligible social care needs; it is recognised that the majority of carers do not receive social care support, and the provision of universal information and support for carers is of great importance.
- Bolton Carers Support is a charitable organisation with funding from the Council

and other sources, which provides a dedicated advice and information service to carers via a bi-monthly newsletter distributed to 3,000 carers, a help line telephone service and other activities. Services are open to all carers aged 18 and over. In 2010-11 there were 2,845 enquiries from carers.

- Specialist advice and support is provided via Job Centre Plus to carers wishing to access employment or training;
- Asian Carers Forum is funded by the Council to provide information and advice and breaks to carers from black and minority ethnic groups.
- Bolton Community and Voluntary Services administers a Short Breaks Grants scheme on behalf of Bolton Council which offers grants of up to £800 for community groups to organise trips out and events for carers.

A survey of carers known to Adult Services carried out in November 2009 indicates that:

- The majority of those that have received support or services from Social Services are satisfied and feel that the support or services have made things easier for them;
- Although the majority of carers (59%) indicated they get most support for themselves as a carer from Social Services, a significant minority (17%) indicate they get most support and services from private agencies;
- Only a quarter of carers had had a break from caring lasting for more than 24 hours over the last 12 months. Nearly a third (30%) of those that had not had a break lasting more than 24 hours indicated this was either because there were no support or services available or because the support or services that are available are not suitable;
- More than a quarter (29%) of carers had had a break from caring lasting between 1 and 24 hours. Over a quarter (27%) of those that had not had a break for a few hours indicated this was either because there were no support or services available or because the support or services that are available are not suitable;
- Although only two thirds of carers had tried to find information or advice about support, services or benefits in the last 12 months, the majority (80%) felt the information and advice was easy to find and helpful (93%);
- Three fifths of carers had accessed support or services for themselves as a carer over the last 12 months and the majority (78%) found it easy to get the support or services they need;
- The majority of carers in contact with health and care professionals felt they were treated with respect and involved in discussions about the cared for person;
- A fifth of carers said that their GP does not know they are a carer.

## **Projected service use and outcomes in 3-5 years and 5-10 years**

The increasingly ageing population means that a greater number of family members will be in the position of providing informal care to older people in the coming years. Many older people are remaining active and healthy for longer, so the need for care may come at a later stage (meaning that carers may be older too when taking on the role) or be more intensive.

Carers UK's 2002 report '*It could be you*' indicates that demographic change, coupled with the direction of community care policy, could see a 60% rise in the number of carers needed by 2037 – an extra 3.4 million carers.

Changes in family formation with, for example, higher rates of divorce and more lone parent families, plus increasing geographical mobility within families, could result in fewer people being available, able -and willing - to be carers. The pressure on individuals to become carers may increase substantially. This could have a significant effect on how families manage to maintain paid employment, how they provide for their pensions, the time they have to spend with their children or other family members and the time they have for social activities; with significant economic and social consequences for individuals and local communities.

Projected increases in numbers of people with particular health conditions illustrate the extra pressure upon carers expected: For example, it is predicted that there will be 60% more people with dementia in Bolton by 2029. More work is required locally to quantify the likely impact of projected increases in the number of older people, those with physical and sensory disabilities and those with profound and multiple learning disabilities on the number of informal carers in Bolton over the next few years.

The expected increase in the number of carers in future years combined with an increased uptake in the use of services by 'hidden' carers could result in a very significant impact on service provision. Given that informal carers are a vital part of the care system as a whole, however, improved support for them to maintain their role for as long as possible could be key to containing costs across the system as a whole.

Analysis of this will be done once more detailed information on local carers from the 2011 Census is released.

## **Expert opinion and evidence base**

Carers at the heart of 21<sup>st</sup> Century families & communities 2008 DH  
Carers (Equality Opportunity) Act 2004  
Dementia Strategy 2009 DH  
Recognised, valued and supported – national refreshed Carers' Strategy DH 2010  
Supporting Carers in Bolton 2009-2012  
Bolton's Carers Strategy 2013-2015

## **Unmet needs and service gaps**

The Council currently commissions a range of support services for carers including advice and information and emotional support, breaks, trips, courses and support groups. Carers with eligible needs receive personalised support and access to respite care and breaks. However, there are many carers who are not aware of potential support and new carers taking on the role every day.

Efforts have been made in Bolton over recent years to reach what have been called 'hidden carers', and outreach, community networks and publicity all have a role to play. In 2009 a high profile publicity campaign was launched to increase awareness of services available. There is potential for a more targeted approach based upon a deeper understanding of needs:

- Carers can join a carers' register at their GP surgery, so that their status is understood in their dealings with the NHS - more work needs to be done with GPs to develop this important area of support and recognition.
- Local carers can join the Bolton Carers Support mailing list to receive a regular newsletter and access events and courses, as well as getting in the information loop which can open up access to the full range of advice and support.
- Improved support and information for those carers wishing to combine employment and caring responsibilities. Carers can request flexible working arrangements from their employers, although this is not widely known and these rights need to be promoted.

Among carers known to services there is evidence of a significant unmet demand for breaks.

#### **Recommendations for needs assessment work**

- Improved understanding of the diverse needs of carers and awareness of the pressures they have and their particular support needs, eg older carers, carers of working age, and carers of people suffering mental ill health
- Improved understanding of the specific needs of carers from ethnic minority groups and barriers to accessing support and information
- Forward projections of the number of carers in Bolton in the future;
- Improved understanding of the support and interventions that can best help prevent the deterioration of health of long term carers and support carers' well-being.
- Improved understanding of carers needs in neighbourhoods where there is evidence of a greater concentration of health problems
- More detailed work is required to explore the issue of unmet needs for breaks for carers and difficulties for people when they try to combine employment with their caring responsibilities. Improved understanding of the benefits of breaks, and different types of breaks, for carers in various caring situations.
- Detailed analysis of the statutory Carers Survey to understand quality of life outcomes for different groups of carers.