

*“Only by having the experience of being a carer do you truly understand the demands, both physically and emotionally, that it has on your own well-being. I don’t believe I went through all of this not to do something with all it taught me. Speaking out on behalf of carers is now my full time commitment. I know what I am talking about because I have been there.”*

Jane, from St. Helens, cared for her daughter who suffered a severe head injury after being involved in a road accident whilst at University.

Three in five of us will become carers at some point in our lives.<sup>1</sup> 301,000 adults become carers in any one year,<sup>2</sup> bringing with them a whole range of experiences, skills and knowledge. Carers get involved in their local communities, in support of other carers, disabled people and older people, because they are frustrated at the lack of appropriate services and through their desire to ensure that other families do not experience the same obstacles as they have.

It is through this contribution that carers become drivers of social change - in combatting social exclusion, increasing carers’ opportunities to combine paid work with care and progressing local regeneration agendas. Too often, carers feel that their contribution goes unrecognised and unsupported. It is vital that we recognise the value of the contribution that carers make, not only to the care of the people they care for, but also to the well-being of carers in their communities and to society as a whole.

### **Purpose of the study**

This report begins to recognise and celebrate the contribution that carers make to their local communities, and to the support and well-being of carers, disabled people and older people. Of the 1600 completed forms returned to Carers UK, 872 indicated that the respondents had been involved in their local community, in support of carers, disabled people and older people. All of the results relate to those respondents who had been involved in their local community.

### **The growth of community involvement**

Over 21 million adults (11 million women and 10 million men) provide their time and expertise free of charge, to their local communities, every year<sup>3</sup>

and many of the statutory services we are familiar with today have grown out of voluntary action.<sup>4</sup> Over recent years, the statutory sector has increasingly sought the views of the community that it serves. There is a growing expectation, often set out in legislation, that carers will contribute to the development of policies and services at both a local and national level, across the UK.

### **How much do carers contribute?**

Despite significant, and often full-time, caring responsibilities, carers in this study have amassed an enormous contribution of 10,953 hours a month - an average of 18.1 hours per carer, per month. Nearly one in ten were putting in more than 30 hours a month, on top of their caring responsibilities. Although similar proportions of carers were involved in the voluntary and statutory sectors, carers contributed 15% more hours per month to the voluntary sector.

### **Who gets involved?**

Carers of all ages, from all backgrounds and in many different situations become involved in their local community in support of carers and the people for whom they care.

Parents of disabled children were far more likely than other groups of carers to be active in their local community.

*“My son was not allowed to go to a local after-school club because of his disability. We had two choices - set something up for him and his friends or go without. We set up our own scheme.”*

Most of the carers involved in this study are currently caring for a partner, relative or friend. Almost one in five were no longer caring, but continue to use their expertise and experience for the benefit of others.

*"I got so much from carers and former carers during the last 10 years. Carers really understand what it is like. I'm glad to be able to give something back."*

### **What drives carers to get involved?**

Carers are driven to get involved in their local communities for many reasons. The two main reasons are the desire to pass on knowledge to other carers and the lack of good quality services.

More than eight out of ten carers said that an important motivator was to prevent other families having the same poor experiences as they had done. The lack of appropriate, affordable and flexible respite and substitute care was another major driver behind carers becoming involved. This was particularly the case for black and minority ethnic carers, parent carers and rural carers.

### **Carers as drivers of social change**

Carers in this study were involved in almost every aspect of service planning, delivery and evaluation, in either an advisory or practical capacity. Within a statutory setting, carers engage with their local council, hospital, GP surgery, health service, job centre and others, attending and sending in written comments to consultations, sitting on committees and providing training to health and social care professionals.

Almost eight out of ten of carers who are active in their local community provide support and contribute to the voluntary and community sector. Carers are involved in core voluntary sector activities, such as setting up new services, running local branches, sitting on committees, helping to co-ordinate activities, providing training, providing counselling, fundraising and campaigning for carers. The value of this is reflected in vibrant local communities that support disabled people and carers.

### **Supporting and involving carers**

Carers contribute a huge amount of expertise, experience and knowledge to the services, support and consultation in which they become involved, across both voluntary and statutory settings.

*"My pre-care experience with social work, social work education, professional consultancy in the Home Office and as a Social Services Inspector all helped me to offer realistic advice to an advisory committee."*

However, 63% of carers did not feel that their caring role or their own expertise had been properly recognised, or that their contribution had been properly supported.

*"They send you piles of papers to read two days before, call meetings at very short notice, and carry on talking when I try to have my say."*

### **Implications of carers' involvement**

Carers' involvement in their local communities has a number of important implications for local regeneration and development, beyond the health and social care agenda. These include:

#### **Routes into paid work**

Carers gain and update key skills through their involvement in supporting carers locally, and help to design and run quality, flexible and affordable alternative care services. The lack of appropriate substitute care is one of the biggest barriers to paid work for carers.

#### **Access to benefits, services and support**

Carers run branches of Carers UK and other carers' groups, encourage 'hidden' carers to identify themselves and write articles for the press to raise awareness of the needs of carers and the benefits, services and support available to them.

#### **Protecting and improving carers' health**

More than 50% of carers in a Carers UK study had sustained a physical injury since becoming a carer, and 52% had been treated for a stress-related illness.<sup>5</sup> The provision of accessible information and support to carers can help to improve the health of both the carers who provide it, and the carers whom they seek to help.

## Innovation and regeneration

Carers are at the forefront of innovation in the provision of services, information and support. *Opportunity for All*, the Government's anti-poverty strategy, outlines various routes through which local people can have an input into local social and economic regeneration initiatives, across the UK.<sup>6</sup> Routes must continue to be found for carers to have an input into these structures and initiatives.

## Measuring the monetary value of carers' contribution

It is difficult to arrive at a UK figure of the value of carers' contribution. An estimated 900,000 carers currently provide over 50 hours of care per week.<sup>7</sup> If 55% of these carers (the proportion of our total respondents who said they were involved in their local community) were each to contribute an average of 18.1 hours per month, their contribution could be worth almost an additional £1 billion per year.<sup>8</sup> This is on top of the contribution they already make to the economy by caring for their chronically ill, disabled or frail partner, relative or friend - worth £57 billion per year.<sup>9</sup>

## Time Banks - a model of recognition and reward

In a Time Bank, participants earn time credits for helping each other - one hour of your time entitles you to an hour of someone else's time. Credits are deposited centrally in the Time Bank and withdrawn when you need help yourself. Help is exchanged through a broker who links people up and keeps a record of transactions through the Time Bank software. Time credits have no monetary value, and so they are unlikely to affect carers' benefit entitlements.<sup>10</sup>

## Key recommendations

*"What carers do should be properly recognised, and properly supported - and the Government should play its part. Carers should be able to take pride in what they do. And in turn, we should take pride in carers." Rt. Hon. Tony Blair, MP, Prime Minister.*

### Government, Assemblies and Executive should:

- \* ensure that guidance makes it explicit that carers' input must be valued. Carers'

contribution must help to shape the development of services.

- \* make it explicit to local authorities, health trusts and other public agencies that good practice in involving carers should be followed.
- \* ensure that their own direct involvement and consultation with carers follows good practice.<sup>11</sup>
- \* take into account the value of carers' contribution to their regeneration, economic development and social inclusion strategies.
- \* ensure that sufficient funding is made available to properly support carers so that they are able to contribute fully.
- \* ensure that ring-fenced funding for key services such as the Carers Grant (in England) is continued and new sources of funding are identified for the Carers and Disabled Children Act 2000, in England and Wales, the Carers and Direct Payments Act in Northern Ireland and the Carers Strategy in Scotland.
- \* ensure that sufficient funding is provided for the development of services in the voluntary sector, and that there is support for carers' organisations at both a national and local level.

### Local regeneration agencies:

- \* Local regeneration agencies should consider how carers' involvement could be recognised and rewarded through Time Banks or similar schemes.
- \* Regional Development Agencies, in England, and Local Enterprise Companies and Social Inclusion Partnerships in Scotland, should take into account carers' role in supporting economic development, as should *'Invest Northern Ireland'* and the Welsh Development Agency.
- \* Local Regeneration and Strategic Partnerships should ensure that carers' roles in supporting community services and in shaping statutory health and social care services are recognised in policies and strategies to combat social exclusion and promote social inclusion.

- \* Particular attention should be paid to the economic impact of carers' role, both in stimulating employment in the voluntary sector and in helping to develop flexible services which help carers return to or remain in paid work.

#### Local authorities and health services should ensure that:

- \* they work together to prevent carers being asked for the same information from different agencies.
- \* carers' time is used wisely and their contribution valued.
- \* good practice around involving carers is followed, including providing training where needed, the payment of expenses, holding meetings at appropriate times, and with sufficient notice and providing feedback.
- \* carers' views actively shape service development. Carers should be consulted and be asked for regular feedback about services to ensure that effective and regular monitoring takes place.
- \* carers' contribution to supporting other carers, such as attending consultation meetings and advising on services, is not confused with the need to take a proper break away from their caring responsibilities.
- \* sufficient funding is set aside to enable carers to become fully involved.

#### Employers:

- \* Employers should recognise and acknowledge the transferable skills and experience gained by carers in their community involvement, in their recruitment procedures.
- \* Employers who are developing or reviewing work-life balance provisions should consult carers on the design and implementation of specific policies and practices, which enable

carers to combine, paid employment with their caring responsibilities.

#### Carers' organisations and the wider voluntary sector:

- \* Carers' organisations should celebrate the contribution carers make to supporting disabled people and carers.
- \* Carers' organisations should seek to increase opportunities for carers to become involved, and promote the benefits of involving carers to the statutory sector.
- \* Carers' organisations should demonstrate and promote good practice around involving carers locally.
- \* Local voluntary sector organisations should recognise the role and contribution of carers to service planning, design and delivery, in the support of carers, disabled people and older people and to the development of local regeneration agendas.

- 1 Carers UK (2001) *It could be you...* Carers UK: London
- 2 *Ibid.*
- 3 Institute for Volunteering Research (2002) *Volunteering - Facts and Figures* National Centre for Volunteering website: [www.ivr.org.uk](http://www.ivr.org.uk)
- 4 Hudson M (1999) *Managing without profit: The art of managing third-sector organisations* Penguin Books: London
- 5 Henwood M (1998) *Ignored and Invisible: Carers' experience of the NHS* Carers National Association: London
- 6 Department of Social Security (1999) *Opportunity for All: Tackling poverty and social exclusion* HMSO: London
- 7 Rowlands O (1998) *Informal Carers: a study of the 1995 General Household Survey* ONS. The Stationery Office: London and DDHSSPS (2001) *Health and Well-being Survey*, Informal Carers Report: Northern Ireland
- 8 Average hourly rate of pay of £9.09 is taken from ONS (1998) 1997 *New Earnings Survey*, as used by the National Centre for Volunteering Research
- 9 Carers UK (2002) *Without Us...: calculating the value of carers support* Carers UK: London
- 10 New Economics Foundation, London Timebank & Timebanks UK (2001) *Time Banks: A radical manifesto for the UK* New Economics Foundation: London
- 11 Social Services Inspectorate (1998) *Quality Standards: Consumer involvement in Community Care Services* Northern Ireland

## CARERS UK



The report *Adding Value: Carers as drivers of social change* is available from Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT (ISBN: 1 873747 23 3) - Cost: £5.  
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