



Disability Rights Commission

CARERS UK
the voice of carers



Women. Men. Different. Equal.
Equal Opportunities Commission

The Future: Who Cares?

The DRC, EOC and Carers UK present major poll findings on the future of caring responsibilities in Great Britain

The Future: Who Cares?

The DRC, EOC and Carers UK commissioned Ipsos MORI to examine public awareness of disability and health conditions and attitudes to the allocation of responsibility for providing support.

The results show that the public has high awareness of people in their circle who are disabled or have long term health conditions; and expects to receive services that match their choices and aspirations if they develop impairments or health conditions. Most said that if they became disabled or developed long term health conditions they would want support to stay in their own home and the choice of not moving into residential care.

The results also show that a significant minority would not be prepared to provide informal care in the future, with no differences in this respect between women and men. A significant minority would also not be prepared to contribute to costs of support, again with no differences between women and men.

Those already providing informal care were more likely to be unemployed or working part-time than full-time. The level of support they provided differed according to their employment position: for instance, people in professional and managerial positions provided far less hours of care than those who were unemployed or working in routine jobs.

In the context of a rapidly ageing population and ever-rising demands for social services, these findings suggest a compelling need to establish models that are effective and acceptable for both people with impairments and health conditions and those who may support them; and that pay attention to aspirations for independent living and employment for both disabled people and their families, friends and informal carers. The fact that women are no more likely than men to be prepared to provide care in future means society may no longer be able to rely as heavily on a private workforce of unpaid women. Flexible models are needed that enable both disabled people and carers to maintain their independence – including engaging in employment and other community activities.

Responding to the survey findings Bert Massie, DRC Chair said:

'Our social care system needs to be transformed so that it can provide real opportunities and meet people's expectations of being able to live independently and to be active, visible citizens rather than the passive recipients of what others deem best. Too many people with significant needs are currently being ignored in formal social care provision. People, but particularly women, do not expect to become the default provider of support due to a lack of public provision. The Private Member's Bill sponsored by Lord Ashley could bring into effect the recommendations made by the Prime Minister's Strategy Unit over 18 months ago and create a social care system that would be able to meet what the public needs now and expects for the future.'

Jenny Watson, EOC Chair said:

'This polling highlights the huge gap between people's aspirations of social care and its reality – a wake up call for us all. There are 6 million carers in the UK today, nearly sixty per cent of whom are women. Many people find they become carers when social care services can't deliver what their relatives want or need, particularly when the only alternative on offer is institutional care. Carers often find it impossible to find work that they can balance with their caring role. As a consequence they face poverty in retirement, something which particularly impacts on women.'

The Government is taking the right steps to enable change, such as extending the right to request flexible working to carers and reforming our outdated pension system. But we also need to see the kind of investment in adult social care that we have seen in the past for childcare, one that is prolonged, systematic, and with services designed around users' needs. Lord Ashley's Bill should be welcomed by us all – because one day, we all may need the support that it provides.'

Imelda Redmon, Chief Executive of Carers UK said:

'Providing care and support to family and friends who need that help because of illness, frailty or disability, though a normal part of life, still goes unseen and unrecognised. Over recent decades we have seen the change in family structure with far more women working, smaller family size and greater geographical mobility. There are currently 6 million people in the UK providing care, 1.25 million of them providing 50 hours or more per week. It is estimated

that within the next 25 years the numbers of people providing care will have to increase to 9 million. At present there are a number of policy collisions that can make life for carers very difficult. There is real pressure for people to remain in work - and work for more years. This is set against a back drop of poor investment in social care and the very low levels of state benefits available to carers.'

Lord Ashley of Stoke said:

'I strongly welcome the MORI poll. The public overwhelmingly expects that if they become disabled or acquire a long-term health condition and need support (which most of us will at some stage in our lives) then that support should deliver more than mere subsistence. The poll shows that people expect practical help and support to stay in their own homes, to carry on with an active family and social life and to contribute to society – and they are prepared to pay for this through their taxes. This is light years away from what happens now, where the vast majority of disabled people rely on family and friends and those who receive social services have no guarantee of much more than being washed and fed. If we are to meet public expectations we need to adopt a master plan which guarantees genuine freedom and choice for disabled people and those with long term conditions. My Independent Living Bill aims to deliver just that.'

Current situation

There are currently 1.7 million people receiving social care services. But the number of just older people requiring such services is set to increase to 1.2 million (a 12 per cent increase) over the next twenty years – assuming criteria and funding continue to be maintained at current levels¹. The population is ageing. In the next twenty years the number of people aged 85 and over in England will grow by two-thirds, compared to a ten per cent growth in the overall population².

The total number of disabled people/people with long term health conditions in Britain is over 10 million. Most do not require social care services. The number receiving support is set to rise given that incidence of disabilities or health conditions increases with age. There is already an unmet need of people seeking social service support and failing to receive it. Earlier this year, the Wanless

¹ The King's Fund, 2006.

² The King's Fund, 2006.

Review culminated in the report 'Securing Good Care for Older People' and it estimated that, if the recommended model of provision were available now, half a million extra older people would be receiving services³. Half of the people assessed to receive services do not go on to receive them⁴.

Many disabled people are reliant on informal support to provide the most basic quality of life. It is not news that the current social service system is unable to meet the needs of modern Britain. The Commission for Social Care Inspection, which monitors social services, reported in December 2005 that:

“Social care services across the country are struggling to meet people's needs.”

- Currently, 6 million people provide unpaid care in Britain⁵. A third of MORI respondents provide care – and know of others who provide care. It is established that care responsibilities are more often undertaken by women than men⁶.
- Nearly 70% of local authorities provide support only to those who meet the highest levels of eligibility criteria – creating a reservoir of unmet need that informal carers must provide⁷. Almost a third (29%) of Attendance Allowance recipients receive no formal or informal support; the eligibility criteria makes clear the need for, rather than receipt of, support⁸.
- Over a third of carers (37%) providing 50 hours support or more per week had never worked or are currently unemployed – removing them from the job market. 78% of all older people with mobility issues are helped by their spouse or other household member⁹.
- The MORI survey shows 45% of all people providing support for people with disabilities/long term health conditions are 'immediate' or 'other family members'. Just 22% of the MORI respondents said that social services provided support – almost the same amount as the 19% who are supported informally by friends.

³ The King's Fund, 2006.

⁴ Department of Health, 2005.

⁵ Census, 2001. A million provide more than 50 hours of support per week.

⁶ National Statistics Online.

⁷ LGA, 2006.

⁸ Wanless, 2006. Attendance Allowance is a benefit available to people aged over 65.

⁹ National Statistics Online.

As many people are supported by social services as are supported by their friends. More people receive support from family members. A reliance on informal support is required to meet the needs of the existing population but this will not be sustainable in the future. One estimate of future informal demand is of a 45% increase by 2026¹⁰. Britain needs a more flexible system, that enables some people to provide informal care but without losing their independence or diminishing their life chances. Demands on other services are also likely to result from a reliance on informal support; for example many carers also experience disabilities/ill health¹¹.

Demand for change in the nature of formal support

An analysis of the MORI poll shows a strong level of support for reform of social services that includes maintaining independence and choice and facilitates independent living. The poll indicates high expectations which we know from research are not routinely met in reality.

The poll results show:

- 90% thought it important to receive support that enables people to live in their own home – rather than be left with no choice but to move into residential care¹²;
- 83% thought it important for services to enable people to visit family/friends; and
- 78% support services that enable participation in community activities.

People expect more from services than simply being washed and fed. For example, being able to see friends and take part in family life are important – people want to be both physically and socially alive.

Half of the people assessed for care do not go on to receive any formal services¹³. The provision of support for visiting family/friends or participating in community activities is not routine – most people

¹⁰ Wanless, 2006 using the PSSRU model.

¹¹ Joseph Rowntree Foundation, 2003.

¹² Nearly 300,000 people are currently supported by local authorities in institutional care (Community Care Statistics, 2004) but there is currently no recourse to legal action for being forced to live in an institution against your wishes. Rising numbers of people with mental health conditions and/or learning disabilities are being placed in residential care – at high costs to local authorities.

¹³ Department of Health, 2005.

who receive a care assessment would not qualify for any such support and would, instead, be made reliant on family and friends for support or left without such opportunities at all.

Respondents anticipate being able to exercise a high degree of choice and control in the event of their requiring social care services – far more than is currently available. For example, 87% of respondents would like the choice of not moving into residential care and 57% would want support from their local authority to stay in their own home – something that is not always possible under the present system.

The future: who cares?

The changing demographic make-up of Great Britain and in particular the rapid growth of our older population, coupled with changes in family structures and the reluctance to provide support reported by some younger people in this survey means that we cannot rely on our existing assumptions or approach to social care. Carers UK have demonstrated that Britain's ageing population, coupled with current community care policy, will mean that by 2037 nearly 3.5 million additional carers will be needed to support the growth in people aged over 75 alone¹⁴. The ESRC more recently reported that the number of 'dependent persons' is set to rise to 70 dependents per 100 non-dependents by 2031¹⁵.

- A third of respondents to MORI (35%) said that they will not or cannot provide care in the future, minimising the informal care market. A third also say they will not contribute towards the cost of care.
- The 15-34 year olds age group are less likely than older groups to say they will provide care in the future (at just 49% compared with 57% for 35-54 year olds). No doubt some attitudes alter with age, but any decline in the level of informal support could cause significant problems for people with support needs, the formal care sector and the Government.
- People working full time also say that they are less likely to provide care in the future than people working part-time (49% to 64%).

¹⁴ Carers UK, 2001.

¹⁵ ESRC, 2006. 'Dependents' are classified using the demographic dependency ratio as people aged under 19 or over 65.

- Lower earners are also less inclined to commit to providing care in the future: 48% of people earning £17,499 and under compared with 57% of people earning £30,000 and over.

The attitudes of younger people are of particular concern. The pool of informal resources the state has previously utilised may no longer be available. Young men and women share very similar ideas for the future on caring – and, as women still provide more care than men, this could limit informal support further in the future.

As the population ages, we will face tough choices about how to maintain economic prosperity whilst providing support to an increasing number in the population who are both economically inactive and requiring care and support. The shifting ratio of young to old will mean far fewer potential carers are available to each person needing support. At the same time, pressure will increase for more people to enter or stay in the job market, further reducing the pool of available informal care. Allied to this are the aspirations and expectations of future generations not to have to provide free care to relatives. New rights to flexible working and financial support to allow people to work part time whilst providing care are important steps. However, they will need to be supplemented by services and support which maximise the independence of older and disabled people requiring support, reducing their dependency on informal care, whilst maintaining rights to dignity, respect and participation in society. In doing so they should be able to maximise the independence and choices of carers too.

Costs of care

The MORI survey revealed that people would be willing to contribute more in tax in order that disabled people and people with long term health conditions could be better supported and in order to reduce demands on informal support through better funded social services.

- Half the public support an increase in tax to fund better social care, whilst just a quarter (25%) oppose such a move – a ratio of 2:1 in favour of higher tax to deliver more and better services.
- 54% of respondents stated they personally would be prepared to pay more for better services.

- Higher earners were more likely to agree to pay more according to the MORI survey: 65% of those earning £30,000 or more, compared with 55% of people earning £17,499 or under.
- A third of respondents (32%) say none of the costs of caring should be borne by the individual receiving support or their family/friends. A tiny minority favoured a policy of all costs being borne by the recipient or their informal carers (4%).

Whilst people seem to be suggesting they will be less available to provide care and support the MORI survey reveals a greater willingness for greater personal financial contributions available for state provision of services.

Next steps

DRC, EOC and Carers UK wish to debate the forms of state provided services that Britain needs now – and will potentially need even more so in the future. The poll findings demonstrate the dangers of failing to recognise or challenge existing assumptions about both the willingness of future generations to provide unpaid care or to tolerate the current status quo in respect of what is provided by public services.

The pressures of an ageing population, changes in patterns of working and family life, and the attitudes of future generations towards care responsibilities and what formal social services should provide, mean that the current reliance on informal care is unlikely to be sustainable. Failure to plan for, and invest in independent living now will be bad news for disabled people – who will not be able to live the lives they want to; bad news for older people and their families – who will be under increasing strain to manage without additional support; bad news for carers, especially women – who will continue to face restricted choices, opportunities and life chances; and, bad news for taxpayers – who will eventually have to pick up the tab if caring stops people being economically independent and if the social support system teeters towards crisis; and bad news for Britain's future social and economic prosperity.

It is clear that this debate is of central importance to the future social and economic well-being of Britain. It is clear that care can no longer be relegated as a 'private matter'.

Social care is going public, and the time has come for a serious debate about the future. Lord Ashley's Bill provides an important and timely focus.

Notes

The Disability Rights Commission was established by an Act of Parliament in 2000 to enforce the rights of disabled people in Great Britain.

The Equal Opportunities Commission was established in 1976 to deal with sex discrimination and inequality related to gender.

Carers UK is the voice of carers and was set up by carers with the vision of people recognising the true value of a carer's contribution to society and where carers get practical, financial and emotional support.

Ipsos MORI conducted the survey in May 2006 via a face-to-face omnibus. The results are based on a nationally representative quota sample of 2,053 adults, aged 16+, interviewed throughout Great Britain.