

Missed opportunities

The impact of new rights for carers

CARERS UK

Executive summary

For more than a decade the UK's six million carers have been increasingly recognised in public policy. It is fourteen years since the publication of the Griffiths Report, which laid the foundations for the NHS and Community Care Act 1990 and acknowledged that public bodies should be doing more to recognise and support carers. In the intervening years two pieces of legislation have been passed – the Carers (Recognition and Services) Act 1995 (CRSA) and the Carers and Disabled Children Act 2000 (CDCA) giving carers new rights. The Government published its National Strategy for Carers, *Caring about Carers*¹ setting out how it intends to improve flexibility and choice for carers. Carers also feature prominently in other social care policies such as the National Service Frameworks for Older People and Mental Health.

There is always a question of how well public policy translates into action which brings about positive changes to peoples' lives. This study sets out to provide some answers. A postal survey was sent to 10,000 carers in England and returns were received from 1695 of them. It examines their experiences of obtaining support services in enabling them to have choices about how they lead their lives, including family life, opportunities to work and maintaining good health. Specifically, it looks at the role played by carers' assessments in identifying and addressing carers' needs. This study also includes a survey of ten local authorities' responses to the policy changes.

Profile of respondents

Carers in this survey are more likely to be at the heavy end of caring than the general carer population – the very carers who are likely to benefit from a carer's assessment. Ninety-five per cent of respondents were providing more than 20 hours caring per week and 71% had been caring for more than five years. All the carers were aged 30 or over with over half (54%) aged 45-64. Over half (53%) were looking after someone aged 65 and above. Thirty-seven per cent cared for an adult between the ages of 18 and 64. A tenth of respondents looked after a child with a disability.

Accessing support

"I have never received any services and none have been offered. I've not been given any information on what might be available. I feel totally ignored by all."

Many carers and the people they care for do not appear to be getting any statutory help. Thirty per cent of respondents reported that the person they care for had not had a community care assessment which is the main trigger for a carer's assessment. Yet 60% of these also reported that they were not getting all the help they needed, suggesting they could benefit from being assessed.

Six years on from gaining new rights to a separate assessment, just 32% of respondents had actually had a carer's assessment – a relatively small improvement from 21% reported in a similar study conducted in 1997.² The reasons for this are clear. Almost half of carers who had not been assessed had not been informed about their rights, a third were not aware of the purpose of being assessed and a quarter saw no point in having an assessment as they believe it would not lead to any extra services.

The assessment

"Things improved once I decided to get a carers assessment. I now get respite care Fridays and weekends, it's really lightened the load."

Carers were asked about the areas covered in their assessment. A key priority for carers is the need for a break, yet only 69% of assessments covered breaks. The National Strategy for Carers emphasised that carers should have choices about employment. Yet only 46% of carers who had given up work or reduced their working hours stated that this was covered during their assessment. Little attention is being devoted to emergency planning – just 28% of assessments addressed this. In contrast, more attention is focused on carers' health. Eighty-one per cent of carers who reported either physical or mental health problems stated that their assessment covered their health.

Do carers' assessments lead to improved support?

"I gave up my job when things reached crisis point. I wasn't getting supported by social services or my GP and in the end I felt I had no choice."

The vast majority of support to carers is delivered by providing services to the person being cared for, such as breaks and help with practical tasks. Having jumped the hurdles to getting a carer's assessment, just 37% saw an increase in services, while for the majority (57%) there was no change. Not all carers' assessments will call for an increase, but 66% of carers who reported that their assessment did not lead to an increase in services also reported that they do not get all the support they need, suggesting significant levels of unmet need. However, it does appear that this worrying picture is improving. Of those carers who were assessed before 2001, only 31% had services increased. Since April 2001 this figure has risen to 42%, which may result from increased levels of funding provided by the Carers Grant.

Of particular concern is that risk to carers' employment does not appear to trigger support services. Just over half (54%) of respondents who had given up work or reduced their working hours saw services stay the same following their assessment – three quarters of these also reported that they were not getting all the help they needed.

The picture for carers with health problems is not much better. Fifty-five per cent of respondents reported that they had significant health problems of their own and 43% had sought medical treatment for depression, stress or anxiety. Yet only 65% of carers with health problems saw an increase in services, raising concerns that too often assessments are overlooking health risks to carers.

Barriers to getting support services

"You can never guarantee to get a worker that you know, you just have to take whoever they have available. It makes me angry as it shortens the actual time out for me, as I have to keep explaining my husband's condition to new workers. To be honest, it has put me off applying for help."

Carers were asked if they got all the help they needed. Two thirds of respondents said that they did not. Just over a tenth (13%) of these said this was solely due to the person they care for refusing help from anyone else. For the remainder service deficiencies were preventing them and the person they care for from getting the right support. Under-investment in social care was much in evidence. With 39% reporting that the service they wanted was not available in their local area, while 28%

were on a waiting list. Nearly a third (32%) of respondents were put off taking up a service due to its poor quality. Problems cited included a high turnover of homecare staff, poorly trained staff, not keeping to the agreed care plan, staff not staying for the allotted time and staff not turning up at designated times. Carers also highlighted the inflexibility of social care services. A quarter of respondents were not able to get services at weekends or during holidays. Others were offered services at inappropriate times – a "putting to bed" service at 6pm when normal bedtime was 10pm. The financial impact of caring is clearly compounded by charging for social care services. Twenty-nine per cent of carers said that charges had prevented them from taking up services.

Overall, there was a sense that carers were unable to negotiate the type of service that would most benefit them and the person they care for. For example, several carers had come up against blanket policies on not providing domestic help which carers wanted in preference to more costly services such as personal care.

Carers' services

"Sometimes I wish I could use some of the direct payments to do practical things around the house such as decorating or gardening, buy equipment such as a suitable wheelchair or transport. All this would help my life as a carer more than help with the personal tasks."

Although the bulk of carers' support is likely to continue to be met by community care services, local authorities have new powers under the CDCA which enable them to provide services directly to carers. The local authority survey found that at best a handful of carers are receiving direct services, which was put down to lack of funding. Six of the ten local authorities had designated funding for carers' services, predominately using the Carers Grant. The increased level of Carers Grant coupled with less restrictive conditions should see an increase in carers' services. This would be welcome by the ten telephone interviewees who were looking after someone who had refused to be assessed or had refused services. None were in receipt of carers' services, but two would like to be offered counselling services, while others wanted cleaning, laundry and gardening services.

Direct payments

"Direct payments are a vast improvement. We have more control over how, when and where care will take place."

There were numerous comments about the positive benefits that carers derived from direct payments –

cash in lieu of services. Most comments were in relation to employment of personal care assistants. Direct payments enabled the person being cared for to have more control over the people they employ, which was greatly valued as was the flexibility and control of times and tasks. Some commented that direct payments had helped resolve difficulties with high turnover of care staff. Carers were clear that they would need help with managing direct payments and in some instances with their responsibilities as employers.

Conclusion

Carers are saving the economy an estimated £57 billion a year,³ but they are getting little return on their investment. Although this study found carers who are getting the support they need, the overwhelming message is that carers are often outside the social care system, unaware of how to access help. Improvements in accessing social care are urgently needed. Carers most often look to their GP for help in the first instance. Some steps have been taken at local level to improve identification and support of carers by primary care staff.⁴ The new GP contract, once agreed, offers incentives in this direction. Primary Care Trusts should ensure that these incentives are taken up. Close monitoring is required of new policy which emphasises the importance of identifying and supporting carers. New technology such as Care Direct offers potential solutions to improving access to social care and should be evaluated from the carer's perspective.

Chronic underfunding of social care is leaving carers to plug the gaps with significant consequences for carers – poor health, no job prospects, strained relationships, even a disregard of their fundamental human right to family life. Investment in social care is not only a challenge for this generation but for generations to come. An increasingly ageing population could mean a shortfall of 2.1 million carers by 2037.⁵ Society and the economy cannot afford to run the risk that increasing numbers will refuse or be unable to take on the caring role.

Government policy has switched the focus of assessments from services to outcomes. This study has shown that one outcome – the opportunity to work – has attracted little attention, let alone resources. Focusing on outcomes rather than services sets a real challenge for local authority budgets to deliver flexible support transparently and equitably rather than being tied to traditional services. *Fair Access to Care* should ensure that the risks to carers are part of the eligibility criteria of local authorities. Performance management which currently focuses on the number of assessments should also address how carers' outcomes are being met.

There are signs of improvement. Since the earlier study, *Still Battling*, the number of carers' assessments has increased, albeit at a disappointing rate. As 2.3 million people take on caring responsibilities each year,⁶ it is paramount that organisations in touch with carers, including Carers UK, regularly provide information on their rights and the purpose of an assessment. This study found that increasingly assessments are leading to more support. The Carers Grant has provided necessary protection from cash strapped social services budgets to improve provision of short breaks. The National Strategy, carers' legislation and the inclusion of carers in national policies, such as the National Service Frameworks for Older People and Mental Health and Valuing People, in relation to carers of people with learning disabilities, have kept carers on the agenda. But there is still a sense that much of this activity takes place at the margins rather than in the mainstream. Nearly two thirds of carers felt there had been no change in services to support carers over the last three years. Hard won rights have yet to deliver real choices for carers.

Recommendations

For Government

- Review progress to date of the National Strategy for Carers, respond to the findings and recommendations in this survey and propose action for the next phase of the National Strategy, including delivering mainstream support for carers.
- Introduce legislation to place a duty on local authorities and the NHS to inform carers of their right to an assessment, bringing England and Wales into line with Scotland and Northern Ireland.
- Substantially increase funding for social care services.
- Continue ringfenced funding for carers' breaks and services and continue funding beyond 2006. Monitor the impact of the Carers Grant through the Delivery and Improvement Statement, including the effect of 'lighter touch' performance management for high performing authorities and social service departments.
- Clarify policy and ensure local authorities have constructed their eligibility criteria for supporting carers in line with Fair Access to Care and CDCA guidance.
- Urgently review the policy on lifting and handling to ensure carers are not exposed to unacceptable risks.
- Develop the performance management agenda to address not just the number of carers' assessments, but the outcomes of those assessments. Develop and publicise workable models that measure outcomes.

For local authorities

- Develop a clear strategy for delivering, where needed, changes in organisational culture and practice in relation to carers.
- Ensure that their care management process is being used to measure outcomes for carers, backed up by quality assurance and inspection.
- Introduce procedures to systematically offer carers' assessments, particularly where the user has refused an assessment or services. Find ways of monitoring the effectiveness of this change.
- Canvass staff attitudes towards carers' assessments and develop new ways of working to tackle unhelpful attitudes, whilst building more constructive ways of linking carers into statutory or non-statutory support.
- Implement training for staff on the CDCA.
- Set clear eligibility criteria for supporting carers to ensure no assumptions are made about the presence of a carer and that no individual is at risk as set out in Fair Access to Care and CDCA guidance.
- Set out their programme for delivering direct payments to service users and carers, including putting in place the necessary support infrastructure.
- Audit assessments to ensure they are needs led and that blanket policies on not providing certain services such as cleaning and counselling have been lifted.
- Urgently review policy and practice on lifting and handling to ensure carers are not exposed to unacceptable risks.
- Abolish charging for social care services, including carers' services.
- Consider ringfencing part of the allocation of the Carers Grant to set up a fund to encourage innovation in providing new carers' services. Promote examples of carers services which have led to good outcomes for carers.
- Ensure contract compliance and that new domiciliary care standards are maintained. Involve carers and users in monitoring services.
- Ensure carers have equal opportunities to employment and consider the role for local strategic partnerships.
- Develop, fund and monitor high quality independent advocacy services for carers and disabled people.
- Local implementation teams of National Service Frameworks and Valuing People should review how they are involving and supporting carers.

NHS and Primary Care Trusts

- Have regard to Carers UK's good practice guide on hospital discharge when reviewing hospital discharge procedures in line with "Discharge from Hospital: Practice, process and pathways".
- Primary Care Trusts should examine referral and signposting mechanisms for carers within primary care, for example to the benefits agencies, voluntary sector and other statutory support for carers.

For carers groups and organisations

- Regularly inform carers of their right to an assessment. Carry out take up campaigns, including participating in Carers Rights Day.
- Audit local authority support services to ensure they are needs led rather than service led.
- Audit local authority handling and lifting policy and its impact on carers and pass on findings to Carers UK for campaign purposes.
- Seek written assurance from your director of Social Services that the local authority does not operate any type of blanket ban on types of services such as cleaning, counselling, or lifting and handling services.
- Ensure local hospital trusts are implementing the new guidance on hospital discharge, including informing carers of their right to an assessment.

References:

- 1 Department of Health (1999) *Caring about Carers: A National Strategy for Carers* The Stationery Office. London.
- 2 Carers National Association (1997) *Still Battling: The Carers Act One Year On*. Carers National Association (now Carers UK). London.
- 3 Carers UK (2002) *Without Us*. Carers UK. London.
- 4 Carers National Association (2001) *Primary Care Support to Carers Practice Briefing*. Carers National Association (now Carers UK). London.
- 5 George, M (2001) *It Could Be You*. Carers UK. London.
- 6 Hirst, M and Hutton, S (2001) *Caring Relationships Over Time*. SPRU. University of York.

Further information

The full report "Missed Opportunities" is available from Carers UK, 20-25 Glasshouse Yard, London EC1A 4JT.
Price £10 plus £3 post + packing
ISBN: 1 873747 26 8

Publications line 020 7566 7626