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Social care practice with carers: What social care support is provided to family carers? What support do family carers want?

KEY POINTS FROM THE RESEARCH

- Most social care support for carers is delivered through the voluntary sector, although most councils still directly undertake carer assessments.
- Changes in commissioning and contracting arrangements have created additional opportunities for the voluntary sector but also some uncertainties.
- Carers have mixed views on the extent to which they feel their social care needs are met. However, they are positive about the help provided by carers' workers with a specific remit to provide them with support.
- Activities by carers' workers are varied and include outreach work, information provision, counselling, advocacy and ongoing support.
- Different ways of improving carers' access to information, such as websites, carers' cafes and outreach workers, have been developed, although these rarely seem to be evaluated for their effectiveness.
- Identifying carers in need of additional support seems mainly to take place when the person for whom they care is assessed. This disadvantages those caring for someone who is not eligible for, or who refuses, social care support from their local authority.
- The Care Act 2014 has implications for the way that social care support to carers is delivered. Currently,

The Care Act 2014 strengthens the rights and recognition of carers in the social care system, including new rights for carers to receive services. In the run-up to implementation of the Act, this study maps different types of social care support for family carers across England.

Using information from commissioners, carers' leads, voluntary organisations, social care workers with a specific remit to support carers, and family carers themselves, this mixed methods study used interviews, surveys and secondary data analysis to ask:

- How do carers access information about social care support?
- What are carers' experiences of assessment?
- What support is provided by carers' workers whose tasks involve providing specific support to family carers?

carers caring for someone not meeting the eligibility criteria for social care support may have substantial or critical unmet needs of their own.

- Carers' organisations argue that an important part of their role is to encourage carers to complete self-assessments but they are concerned that not enough support is then available to those carers who have been assessed.
- Some local councils are working with local clinical commissioning groups on integrating support for carers, though these developments have yet to become established everywhere.

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NHS
National Institute for
Health Research



- Personalisation has brought mixed benefits; with some positive examples of carers having more control over their support but some concerns that the preferences of carers who simply want a regular and reliable break are not being properly met.

BACKGROUND

Better ways of supporting carers providing unpaid care are needed to help prevent the negative consequences that prolonged intensive caring sometimes has. Otherwise, it will become increasingly hard to support the growing numbers of older adults and people with disabilities needing support.

The Care Act 2014 created a number of new rights for carers. It aims to place carers on an equal footing with those for whom they care in terms of rights to support. Local councils with social services responsibilities (CSSRs):

- have a duty to assess carers' needs for support (not just those defined as providing regular and substantial care) and to meet those needs if carers are eligible;
- must ensure that carers and service users have information and advice about the support available in their locality; and
- should use the principle of wellbeing when defining outcomes for carers and people using services.

FINDINGS

Commissioning

Carers' organisations and carers are involved in planning services but this is mostly based upon consultation and feedback from surveys rather than being carer-led.

Carers would like those commissioning and providing social care to recognise that carers are often supporting people with complex overlapping physical and mental health needs.

Commissioners and carers' leads said they wanted to make health and social care support for carers more integrated.

Most of the developments they described were in their early stages, but they hoped that it would become easier for carers to find out about the support available and that integrated carer support would be more cost effective.

A positive example of integrated support comes from a carers' centre that receives local council funding to run its service. The centre works with a local NHS Trust to provide counselling and education for carers experiencing particular difficulties with their caring role through the Improving Access to Psychological Therapies (IAPT) programme.

Local councils are moving towards outcomes-based commissioning whereby services are defined and paid for on the basis of a set of agreed outcomes for those using the service. Some providers take issue with the way that these outcomes are defined, while others want more support in developing bids to provide carer support services.

Funding

Everyone is aware of the need to achieve efficiency savings but carers' organisations and carers worry that carers are being unfairly affected by reductions in social care expenditure because it is assumed that they will continue to provide support.

The contribution made by local councils to supporting carers is often hidden. Most social care support for carers is delivered by other organisations, so organisations and individuals often view local councils as peripheral, even when the council has funded specific services or carer support worker posts.

Identifying and supporting carers

Only a small proportion of carers receive any type of social care support, even so-called 'universal' services open to everyone irrespective of their needs or financial circumstances. Those taking part in this research offered a number of reasons for this:

- Many people caring for family members or friends with disabilities do not identify themselves as carers. Family carers often describe themselves as caring for many years before recognising themselves as a carer.
- Carers sometimes think the process of applying for, and receiving, a carer's assessment will be too cumbersome in relation to the amount of support that they can expect to receive.
- Feelings of stigma or guilt can be barriers to asking for help.

Information

Examples of initiatives aimed at improving carers' access to information include information stalls, publicity campaigns, and funding for specialist outreach teams or workers but the advantages and disadvantages of these different approaches do not seem to have been evaluated systematically.

Many family carers describe difficulties in accessing information but neither do they want 'information overload'. They want information that is timely, relevant, and personalised to their specific circumstances. They do not want to be given too much irrelevant information at a time when they feel too stressed to absorb it.

Carer assessments

Few carers find out about their rights to an assessment themselves so carers' centres and other carers' organisations play a vital role in helping carers recognise their rights. Their staff also sometimes take part in assessment visits to give the carer moral support or, occasionally, take on a more formal advocacy role.

Most local councils still undertake assessments in-house. There are some examples where carer assessments have been outsourced to voluntary organisations. An alternative model is to fund workers in a carers' centre to assist carers in completing self-assessments. This is especially important for reaching carers with sight or literacy problems or for whom guilt and stigma are barriers to asking for help.

Excluding self assessments, most carer assessments seem to be incorporated into assessments of the person cared for. It is not always clear whether support is being provided on the basis of the needs of the carer or the person cared for. In many instances, this may not matter but carers whose own needs for support are greater than those of the person for whom they care may lose out under this system.

Some voluntary organisations and carers' workers consider that the access and screening teams operating within or on behalf of adult services departments need to become more adept at recognising carers' needs.

Personalisation

Personalisation, particularly in the form of direct payments, can provide carers with more tailored and practical support, such as

- Driving lessons for a carer living in a rural area with no public transport who had rarely been able to leave the house previously
- A bus pass for a carer on a very low income so he can visit his father more frequently and provide him with more day to day support
- A day at a spa for a carer caring for an adult child with very high support needs to give her a break from caring

In most instances, this support is funded through a one-off payment. In one study area, a decision has been taken to continue offering an annual grant to all those caring for someone with eligible needs without means testing. In another, the carer's grant has been replaced with a means tested carer's personal budget.

However, personalisation has also created some tensions between commissioners and some carers' organisations and family carers who argue that it creates additional work for carers who have to manage the personal budget of those for whom they care if they lack capacity or are too unwell to manage it themselves. They consider that carers who may be caring for someone who is very physically frail or terminally ill or who has severe dementia would prefer a regular and reliable break from caring instead of a direct payment.

Individual Service Funds offer one solution to this dilemma. These involve councils paying the personal budget to organisations providing support but the carer and person cared for retain flexibility in terms of what is provided. One organisation taking part in this research is considering setting up Individual Service Funds but is unsure if this is feasible.

Some parents of adult children with a learning disability also criticise what they see as inflexibilities in personalisation. They are concerned that contracts have been made with supported living providers (a way of combining housing and support aimed at helping people live more independently) with very little possibility to choose alternatives.

Carers' workers

Many local councils and organisations have developed posts with a specific remit to work with carers. These posts are more likely to be funded on a temporary basis or on a fixed term contract than other social care jobs.

Although some workers are funded to undertake a specific role or to work with a specific type of carer (e.g. carers of people with a particular illness or condition), most undertake a range of activities. These include information provision, counselling, outreach work, advocacy and ongoing support.

Carers' workers drew a strong distinction between information delivery and information processing. They argue that carers are often given information in a scattergun way and that other professionals do not spend enough time going through it.

Social care workers working exclusively with carers account for around 1% of the social care workforce but around 13% of social care workers have subsidiary roles in supporting carers. These are mainly home care workers helping carers deliver personal care. Carers and carers' organisations highlight the importance of their work in giving carers a regular break or providing a 'listening ear'.

By contrast, the role of social work appears to be almost invisible in this study, other than in undertaking assessments.

IMPLICATIONS FOR PRACTICE

More information does not necessarily mean better information. Carers and carers' organisations could help review the quality of information provided by adult services departments on the basis of its relevance and accuracy.

Information provided through leaflets and websites is unlikely to reach some groups of carers: those with literacy problems, who do not use computers, who do not recognise themselves as carers or who feel unwilling to ask for help because of stigma or guilt. Additional outreach strategies will be needed, such as targeted campaigns or funding workers with a specific remit to identify carers in a particular community.

Social care helpline and access teams

ABOUT THE STUDY

This was a mixed methods study with four main strands, including in-depth interviews with 24 family carers, 8 commissioners, 16 representatives of voluntary organisations and 38 carers' workers in four parts of England; 80 responses to an email/postal survey sent to all local authorities with responsibilities for adult social care (50% response rate); a web audit of 50 local authority websites; and secondary analysis of the National Minimum Data Set for Social Care (NMDS-SC) data on carers' workers.

The research was conducted by Jo Moriarty, Jill Manthorpe, Michelle Cornes and Shereen Hussein of the Social Care Workforce Research Unit, King's College London. The Project Advisory Group and Social Care Workforce Research Unit Service User and Carer Advisory Group provided advice and support. Carers and carers' workers commented on these findings in five separate workshops.

potentially provide preventive social care support to carers but councils need to examine how effective these teams are in identifying those carers most at risk of experiencing difficulties in their caring role and offering them acceptable and appropriate support.

More attention should be given to carers' needs for emotional support. Carers' centres and carers' workers are a vital source of this support for carers but they are not in touch with all carers.

Carers appreciate the range of support that carers' workers offer. In particular, the value of regular support from a 'known' person is emphasised strongly.

Many carers are still unaware of their rights to an assessment, despite the length of time that has passed since this legislation was passed. This has implications for the implementation of the Care Act 2014.

The degree to which personalisation policies and processes are sensitive enough to meet carers' needs should be considered. Direct payments suit some but not all carers, yet alternatives appear to be limited.

There are opportunities to evaluate different models of providing information for carers and the outcomes of different assessment models.