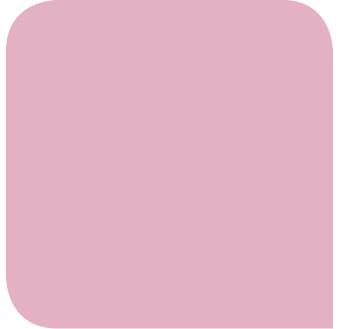


Working together: Carer participation in England, Wales and Northern Ireland: A summary



Carer Participation Position Paper Summary

Introduction

The participation of carers in the change and improvement of services is part of central government's modernisation agenda for health and social care across UK counties. Legislation, policy initiatives and action by carer and supporter organisations themselves have led to attempts to put these policies into practice.

The position paper aims to identify good practice in carer participation through:

- A review of the literature, including published and unpublished material
- A practice survey across the UK covering the statutory and voluntary sector in social care, NHS and primary care trusts, joint trusts, learning disability partnership boards and carers' organisations

The work is premised on the belief that carers are experts in their own lives, and that participation in service planning and delivery should lead to improvement in those services. The work has been carer-led from the outset.

A carer participation reference group including carers from diverse backgrounds made sure that the research team looked at things that are

important to carers, and that carers would be able to understand what the research was saying.

Key findings

Are carers participating?

Carers are participating in different ways, and there are some examples of creative and supportive carer participation in both statutory and voluntary contexts.

There is as yet no consensus on what 'carer participation' means. Carer participation is construed as ranging from consultation to direct involvement in shaping the outcome of carer services.

The research shows that carer participation has focused mostly on consultation-type activities, rather than carers being fully involved in service design, delivery and review. However, the practice survey suggests that, in some cases, carer participation in service planning and review seems to be happening at a strategic level.

Are all sorts of carers getting involved?

It is crucial that carers who may face multiple types of oppression in their wider lives are fully accounted for in their views of carer participation.

The literature that includes black and minority ethnic carers is growing, but there are few studies of the involvement of black and minority ethnic carers *per se*. The evidence available suggests that carers from black and minority ethnic groups are more likely to be involved in consultation, rather than full decision making participation activity. The assumptions that black and minority ethnic people 'look after their own' is still pervasive in the literature.

There is very limited knowledge about the recognition and participation of gay and lesbian carers.

The practice survey showed little activity aimed specifically at carers of people with substance misuse problems or other stigmatising conditions. A significantly high number of organisations said they did not have a policy for reaching hidden or marginalised carers.

How is carer participation happening?

Carers' organisations are playing a key role in activating and substantiating carer participation and guidance. These activities are funded by the Carers Grant, and additional finance is received from major national voluntary sector providers, and occasionally from European Social Fund or Single Regeneration Budget funding.

Some of the most developed forms of carer participation include involvement of carers in key recruitment roles for posts related to carer participation and major programme review and change.

Here are some examples of how carers are participating in service planning and delivery decisions:

- Through being a member or chair of the carers' forum
- A carers' sub-group of local implementation team
- Carer members of cancer and palliative care review board
- Through board meetings – e.g. joint health and social care
- Advocacy partnership group
- Carers' modernisation team
- Parent-carers' forum
- Mental health carers' forum
- Carers' strategy group
- Multi-agency carers' strategy group
- Carers' sub-group of partnership board
- Health and social care improvement board
- Regular bi-monthly forums open to carers of
 - > older people
 - > people with mental health problems
 - > and people with learning and/or physical disability

How good is the evidence?

Most research and writing is based on small-scale, qualitative studies. These are valuable but tell us little about the broader, quantitative picture of carer participation.

There is limited crossover between the voluntary sector and academic research. Very few academic studies cite major quantitative studies available in the voluntary sector.

It was difficult to try and identify the particular needs of different kinds of carers, because in the majority of research age and gender is the only information given to differentiate between carers.

Few studies focus on statutory follow-up or monitoring activities after carer participation has taken place. This might suggest that the full process of carer participation is not yet being evaluated, and so its impact is unclear.

What is the situation with individual carer assessments?

According to carers and statutory agencies, individual carer assessment was one of the least consistent and least satisfactory elements of carer participation. Studies of carer assessments, while suggesting greater awareness and use of such assessments, indicate that their use is

patchy and that outcomes are often limited or not forthcoming.

The practice survey showed that the area of carer assessment is the area where expectation and delivery are most mismatched. Some carers seemed unaware of their right to an assessment, while others were unaware that they had had one. More could be done to make carers aware of their right to an assessment.

Carers feel that firmer guidance and adherence measures are needed to ensure that carer assessments are completed and acted on. What it is and what it is not reasonable for local authorities to encourage carers and carers' centres to do is a very important question.

Assessment training for practitioners was felt to be more effective if presented by carers as problem-solving exercises about their actual experiences, rather than training in how to do paper-based assessments. In some cases a performance management culture has resulted in assessments being output, rather than outcome, led, using numerical rather than quality life criteria. This has also led to time pressure which is unhelpful to carers needing to consider carefully what their support needs are.

What sort of barriers are there to successful carer participation?

There is as yet no shared standard practice or definition of carer participation. This can mean that carers are consulted about decisions rather than being directly involved in making them.

Respite care is central to carers being enabled to participate, to develop greater autonomy, and to have a break from the strain of caring. However, the literature strongly indicates a shortfall of provision against carer expectations.

More could be done to identify and increase the participation of historically 'hidden' or marginalised carers. Not surprisingly, some of the most innovative work is being undertaken in localities with significant ethnic and cultural diversity.

Funding and professional and organisational cultures are seen as obstructing consistent partnership working. Some organisations, especially health trusts, are felt not to perceive carer participation as 'core business'.

Lack of resources was commonly cited by carers, carers' centre staff and statutory professionals as one of the main reasons for lack of involvement at individual carer level. The most common points from carers related to difficulty getting hold of social work staff except in emergencies or only after prolonged efforts.

Tight budgetary allocations determine the practice of social care professionals at the same time as they are being encouraged to engage carers more fully. This may limit the extent to which carers' views are being formulated into service metrics that equate to firm service outcomes.

What works in carer participation?

Most well-established carer participation schemes involve carers at both strategic and grass-roots level, and include feedback mechanisms that ensure carer input makes a difference to service delivery.

Funding individual carer's time was the prevalent form of resource support. This was paid either directly or through carers' organisations. Carers Grant monies were the main source of revenue.

Some in the statutory sector feel that more guidance networks would be useful in cementing best practice ideas into service standards and delivery.

Some of the most creative inputs to carer-centred work are being undertaken by primary care trusts supporting substantial staffing input. However, primary care and health trusts are also more likely to state that carers are not seen as 'core business' and, so, often receive non-recurrent funding.

In some local authorities, 'modernisation and reform groups' are being used to embed their carer participation work in a successful way. This has helped to promote more seamless cross-departmental working.

Some statutory organisations express the view that where targets have been set (such as, Valuing People or the National Service Framework for Mental Health) there is more carer participation. However, the practice survey also found that there is a risk that carer issues outside statutory targets may not be addressed.

There are some examples in the literature and in practice that point to creative joint commissioning and provision of carer participation support. Some of the most innovative activity is being funded and provided by social services departments, primary care trusts and health trusts, for example in the mental health and learning disability areas.

Power sharing should lie at the heart of a progressive shift to the fullest carer participation.

Are there similarities with user participation?

Like carer participation, user participation is on the agenda, but not yet fully realised in practice. The difficulties with organisational cultures, power sharing and stable funding are the same as those experienced by service users.

The experience of having consultation exercises rather than strategic decision-making power in service development, and a lack of feedback about participation exercises is similar in both groups.

Both users and carers from black and ethnic minority groups and other marginalised or 'hidden' groups, including the lesbian and gay community, are still facing difficulties in being heard.

At present neither user nor carer participation activities are being properly evaluated so the impact on service outcomes that make a difference to peoples' lives is not yet clear.

Conclusion

The position paper shows that more needs to be known about:

- Tools for evaluating effectiveness and impact of carer participation
- Factors that mediate between strategic and grass-roots carer participation and impact on services
- What works to increase the involvement of 'hidden' and marginalised carers (including lesbian and gay carers and carers of those with substance misuse problems)
- The 'expert carer' phenomenon

Overall, the current picture suggests that carer participation (including individual assessments) is firmly on the agenda. However, the extent to which it is functioning and evaluated is not clear. The impact of participation on meaningful outcomes for the lives of carers is still open to question.

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