

Developing user- and carer-centred community care

Sustained initiatives to involve users and carers across the range of community care activities can transform care provision - but only if there is sufficient investment from both sides. Four local authority case-study sites reported significant changes in the way care was planned, managed and delivered. Users, carers and staff working together over two years in four project teams stressed the following:

- **User and carer involvement for its own sake is irrelevant. Its success should be measured by service changes that have demonstrably improved lives.**
- **The first step to effective user and carer involvement is the development of good two-way communication. This is most effective when users and carers help design and lead the consultation process.**
- **Once users, carers and staff can communicate effectively, organisations must change in ways which make it possible to respond rapidly to user and carer perceptions and judgements. Users and carers can play a vital role pinpointing problems and helping managers and staff to solve them.**
- **Users and carers helped produce improvements not only through community care planning but at all levels of management and service delivery: improving systems, designing training, developing new projects, boosting quality, planning wider networking and consultation.**
- **The changes required to equip an organisation to work effectively with users and carers are also necessary for the organisation to achieve greater efficiency and better matching of services to user and carer needs and choices.**
- **Users and carers also found that they changed - and had to learn to define new roles, to undertake training and development, and to negotiate support for and limits to their work.**
- **Partnerships recognising equal but different expertise between users, carers and staff and based on agreeing common aims and pooling resources were found to be the most effective working relationships.**
- **For relationships to evolve into real co-working, statutory bodies had to support users and carers - through direct payments, access to training, transport etc.**
- **The project experimented by offering cash payments to user and carer groups, and asking them to decide how best to use them. This proved far more effective and empowering than payments in 'kind'.**

The *From Margin to Mainstream* project was designed to encourage the development of user- and carer-centred community care. An initial survey showed that many authorities had already begun to involve users and carers - but that these initiatives remained experimental - on the margins. The project aimed to help those authorities to take the next step and move user and carer involvement into the mainstream. Four case-study sites with a track record of user involvement were chosen - Dyfed, Hereford and Worcestershire, Sheffield and Sutton.

Significant strides were taken within relatively short timescales to involve users and carers in all areas of care planning, management and delivery. For example:

- A co-operative of people with disabilities in Llanelli has formed the core of the Dyfed *From Margin to Mainstream* project, extending user-run information services across West Wales to Aberystwyth, Carmarthen and Pembrokeshire. The group has taken an active part in community care planning at all levels (including the top), in rethinking assessment processes, drawing up new complaints procedures, and delivering as well as receiving training.
- In Hereford and Worcestershire, a project to involve elderly people with mental health problems and dementia has created a resource-network of carers, led to real dialogue between social workers and carers about thorny problems and to a reversal of attitudes which dismissed the views of both people with mental health problems and their carers as 'too involved'. People with dementia are now consulted about their care.
- In Sheffield, a user-led network drew up and disseminated a Charter for People with Disabilities, set out their own business plan and invited the local authority to discuss it. They now regularly meet senior managers within social services, health and housing to influence planning and purchasing of community care services. A user has been appointed as a development worker, with users involved in the appointment, and in drawing up the work plan.

- In Sutton, what began as a project to consult users about a new day centre - has become a user-managed learning centre for people with disabilities, with a user-led board offering the service as an independent provider under contract to the local authority. Other projects involve recruiting people with mild learning difficulties to act as buddies and advocates for people with severe learning difficulties, and working with GPs to extend carer consultation in primary care.

Why involvement?

Users and carers throughout the project stressed that they were not interested in involvement as an end in itself. Indeed, from their point of view it takes time and energy - scarce commodities for those with frail health. The success of initiatives to involve users and carers should be judged not by how many people take part but by the amount of change that takes place in the services people receive and the quality of their lives.

Successful user and carer involvement does not simply benefit users and carers. It plays an essential part in achieving core organisational goals, meeting the legislative requirement to be needs led, developing appropriate services that add value, making the best use of scarce resources. Care organisations that have no input from service users and carers cannot be said to achieve their social objectives.

A two-stage journey

User- and carer-centred services cannot be created overnight, they are best built up in stages, establishing two-way communication; and then using it to change services. Improving communication on its own is not enough.

Stage One is about helping staff to talk to users and carers, helping users and carers to formulate and put their views and ensuring everyone listens to and takes note of what the others are saying.

Stage Two is about producing service change. Even with good two-way communication this is hard, since it often involves challenging values, priorities and well-established patterns of working. Users and carers also have to change. The key to overcoming the obstacles that face both users, carers and staff is for them to collaborate as 'change agents'.

The case-study sites found that the following strategies helped to influence organisational change:

- Linking the purpose behind user and carer involvement to important organisational goals. The argument went “help us to help you to ... become more efficient, reduce waste, meet targets, consult users more effectively etc”.
- Making it clear that involvement was even more important at times of cuts to ensure best use is made of the remaining resources from the viewpoint of users and carers.
- Helping to change staff thinking and behaviour in ways which didn't lead to defensiveness. Users and carers saw their role as educators and persuaders, and stressed the need to see staff as whole people, and to understand their perspective - to recognise the need for two-way learning.
- Ensuring plans are implemented. Often users and carers were involved in elaborate plans which didn't always translate into action. They could play a powerful role in chasing up plans and checking implementation.
- Creating a 'win-win' view of power. When users and carers gain power professionals, managers and politicians do not necessarily lose power. Once others understand user and carer perspectives, they also gain knowledge, capability and power.
- Enabling users' and carers' needs to be met in the round by collaborating across organisational and sector boundaries. Users and carers use their 'non-aligned' and 'ultimate customer' status to facilitate collaboration.
- Making it easy for managers and professionals, with busy and pressured workloads, to integrate users and carers into their work. Users and carers being easy to contact, reliable and willing to spend time informing and educating staff.

Change also affected the users and carers involved in the projects. They had to learn about:

- Balancing the time and resources to be spent on self-help group activities with those needed for involvement in care planning. Learning to take control of demands on their time. For instance, deciding how best to influence the community care plan and explaining to staff that they wanted to reduce the number of meetings, or to streamline ways of working.
- Disentangling confusing and sometimes conflicting roles as dependent individuals, as advocates, lobbyists, advisors, partners etc. It helps if community care organisations understand the different roles, and recognise the value of campaigning and advocacy as well as collaborative participation.
- Resisting the pressure to speak on behalf of other users and carers where this is not appropriate.
- Avoiding burn-out. Users and carers can face increasingly unrealistic demands on their time. It is important that they find ways to support each other in setting realistic expectations, and are offered the sort of support that staff would have to take part in activities (full information, access to telephones, printing, meeting rooms etc.).

Providing support for users and carers

The study explored ways of providing resources directly to service users and carers to enable them to take part. Funds were allocated to each case-study site which had to be matched by the local authority, and which were available to be passed on to users and carers for them to buy what they needed. The funds were used to buy communication aids, including interpreters, provision of signers, tape and Braille - to obtain working facilities (transport, office space, photocopying, phone calls) to provide respite care, to pay for travel and hotel bills to attend meetings, and to pay for training.

The impact of enabling users and carers to purchase directly their own support was different to that of providing support in kind. Local authorities routinely make available transport, meeting rooms etc. These are welcomed. However, when users and carers are provided with money to buy their own support, they report extra benefits, a greater feeling

Table 1: Different types of user, carer, staff working relationships in planning and developing services

Aspect of the relationship	Type of relationship				
	No involvement	Consumer education and 'marketing' services	Limited two-way communication	Listening and responsive	Partnership
Who defines issues and problems?	Staff define issues and problems	Staff define issues and problems	Staff define issues and problems	Users and carers consulted about issues	Users, carers and staff together define issues and problems
How is information collected?	Organisation uses its own information and requires staff to 'speak for' users and carers	Use of market research to elicit user and carer views	Use market research and limited consultation to elicit user and carer views	Open consultation processes with a wide range of user and carer groups, voluntary organisations and individual service users and carers	Users, carers and staff share in information collection
Who thinks up solutions and decides actions?	Staff develop solutions in isolation	Staff use the information they have collected on user and carer views to develop solutions	Staff develop options and then consult with users and carers	Users and carers involved in analysing problems and discussing options	Users, carers and staff work together to solve problems and decide appropriate action and implement decisions
What support is provided to users and carers?	The minimum required to meet statutory consultation requirements	Resourcing consumer education	Support to user and carer groups to enable them to take part in consultation	Support to individual users and carers, self-help groups and voluntary organisations in a range of ways that help them develop skills and knowledge	Users and carers work alongside staff to plan the support they need. Users and carers also provide support to staff

of control, of being valued, and of being able to make choices.

Payment to users and carers affects their roles. Users and carers had to distinguish between the different roles they were being asked to perform, and to work out what sorts of payments were appropriate in each role. For example, in their role as citizens, they felt entitled to resources to enable them to take part, but not to individual payments. As advisors or trainers, however, fees might be appropriate.

Partnership

The most important change identified by the study was a change in the relationships between users, carers and staff. They challenged the assumption that services are 'products' delivered by skilled staff and instead evolved collaborative relationships between users, carers and staff.

Participants increasingly put emphasis on the need for relationships of partnership. Their definition of partnership was a precise one:

"A group of people who have agreed a common aim and who will pool their resources in order to achieve it."

It is a relationship of equality - and involves a recognition of the equal but different expertise of users, carers and staff.

Common aims are developed by all partners having an equal say in deciding both the scope of the group's work and its aims. As users, carers and staff may have similar but also different interests this cannot be achieved without some negotiation. Establishing what are the differences and common ground takes time, tolerance, a willingness to listen and good two-way communication. Relationships of partnership open the possibility of users and carers participating in all aspects of care. This does not mean everyone contributing to everything, but it means being able to choose whether and how best to take part.

Partnerships cannot be created overnight, they are best built up in stages. Changes in

communication, in the way organisations respond, in user and carer roles, in the support offered to users and carers, in staff attitudes and training - are all part of the necessary groundwork. There is a danger that becoming more ambitious about the quality of relationships between service users and providers will simply mean that some people will be excluded, either because it is assumed they cannot know what is best for them or because of a failure to think systematically about all those to whom services are directed.

The challenge now is to use learning from the project to create new ways of talking to previously excluded groups about their needs. Some progress has been made in the case-study projects in overcoming the barriers to participation for users with dementia and other mental health problems and those with severe learning difficulties. Partnerships will not be achievable in all situations. However, changes in relationships which fall short of partnerships can also change the planning, management and provision of care for the better. Table 1 sets out five 'types' of relationships on the way to partnerships.

In complex organisations it is highly likely that all five types of relationships will exist at the same time. For example the same group of staff may have developed 'partnership' relationships with one group of users and carers whilst having only established a 'limited two-way communication' relationship with others.

There can be a tendency to pour cold water on user and carer involvement initiatives that fall short of the ideal of partnership. Equally where partnerships exist unless they are perfect they can be damned for their imperfections. This type of criticism can be very destructive and can demoralise both users, carers and staff. Any movement towards user and carer involvement is a step forward and something to be celebrated. However, having a view of how ideally things should be both puts progress into perspective and helps people think about further developments.

About the study

Four case-study sites with a track record of user involvement were chosen - Dyfed, Hereford and Worcestershire, Sheffield and Sutton. Over two years, staff and users and carers worked together to extend user and carer involvement. The case-study sites were supported by consultants from the Office for Public Management who also facilitated meetings between sites and practice exchange meetings with a wider network. Each site was provided with a budget of up to £10,000 to be matched pound for pound by the local authority. The money was specifically for use by the users and carers involved in each project to buy the support they required to participate in community care.

Further information

The overall project report *From Margin to Mainstream: Developing User- and Carer-Centred Community Care* is published by the Joseph Rowntree Foundation in association with *Community Care* magazine. It is available, price £9.00, from BEBC Distribution, PO Box 1496, Parkstone, Poole, Dorset BH12 3LL, Tel: 01202 715555, Fax: 01202 715556.

Initiatives in User and Carer Involvement; a survey of local authorities; Charting the Implementation Route: progress on user and carer involvement; Paying Users and Carers for Their Involvement in Community Care; User and Carer Involvement in Community Care: A Manual for Managers, Volumes 1 and 2 are available from Office for Public Management, 252b, Grays Inn Road, London, WC1X 8JT; Tel 0171-837-9600, Fax 0171-837-6581.

Related Findings

The following *Findings* look at related issues:

Social Care

- 27 Involving disabled people in community care planning (Sept 92)
- 29 Self-advocacy and people with learning difficulties (Jan 93)
- 31 Involving disabled people in assessment (Mar 93)
- 33 Implementing care management (Apr 93)
- 37 The effectiveness of an Independent Living Advocate (Sept 93)
- 42 Citizen advocacy and people with learning difficulties
- 45 Development and training for self-organised groups of Disabled people (Jan 94)
- 48 Evaluation of an independent living skills training project (Mar 94)
- 49 Disabled people and community care planning (Apr 94)
- 50 User empowerment and the reform of community care (May 94)
- 56 Independent organisations in community care (May 94)
- 59 Involving older people in community care planning (Nov 94)
- 60 Self help groups and professionals (Nov 94)
- 61 Employing personal assistants (Jan 95)
- 63 Local authorities' use of Independent Living money (Feb 95)
- 65 Care management and assessment from an anti-racist perspective (Mar 95)

For further information on these and other *Findings*, contact Sally Corrie on 01904 654328 (direct line for publications queries only; an answerphone may be operating).



Published by the
Joseph Rowntree Foundation
The Homestead, 40 Water End
York YO3 6LP
Tel: 01904 629241 Fax: 01904 620072
ISSN 1356-3416

The Joseph Rowntree Foundation is an independent, non-political body which funds programmes of research and innovative development in the fields of housing, social care and social policy. It supports projects of potential value to policy-makers, decision-takers and practitioners. It publishes the findings rapidly and widely so that they can inform current debate and practice.