Evaluating community care: a guide to evaluations led by disabled people.

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Cover

The cover features a line illustration of a jigsaw puzzle piece. Inside the jigsaw piece there is a line drawing of a person in a wheelchair, and a blind person using a cane, atop a set of hanging scales. The scales are balanced and on one side are the words ‘care management’ and on the other ‘assessment’.

Three logos are featured:
- The Prince of Wales Advisory Group on Disability
- Living Options Partnership
- King’s Fund

Inner title page

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Introduction

The community care reforms introduced by the NHS and Community Care Act 1990 have brought about substantial changes in the way community care services are financed, planned, organised and provided. While these arrangements are expected to take at least ten years before they are fully implemented, the success of the new legislation will be judged ultimately by its impact on the lives of the people using the services.

Commissioners and providers of health and social care are increasingly interested in finding out how users experience services and what effect they have on people’s quality of life. Both want to know if services are meeting identified needs effectively and providing value for money. Both want to identify strengths and shortcomings in current services in order to maintain quality and improve provision where necessary. Service evaluation is thus becoming a vital component of the service development process.

Disabled people clearly have a central role to play in evaluating community care. It is their needs, experiences and views that matter when it comes to assessing the merits of the services that they use. Their ideas and suggestions for change are also an invaluable part of the evaluation process. As shown here, evaluations which are controlled and undertaken by disabled people themselves have distinct advantages, enabling them to focus on their own priorities and empowering them in the process.

Historically, disabled people have been passive recipients in evaluations. They have been the subject of the evaluation and have had little control over the design or implementation. Recently, there have been a number of evaluations led by disabled people where they have been active participants, and the service has been the subject of the evaluation.

This publication demonstrates that user-led evaluation provides valuable insights into service quality. It shows how, through such evaluations, users provide detailed feedback to commissioners and providers about services and identify ways to achieve specific service improvements. It also offers advice on practical ways to undertake user-led evaluation, drawing on the experience of two projects supported by Living Options Partnership during 1994/5.

User-led evaluation of community care is still in its infancy and, where it has taken place, it has led to positive changes in the way service organisations work. These early initiatives have also demonstrated how effective partnerships can be achieved, as disabled people and service agencies work together to improve health and social care provision.

User-led evaluation: What is it?

Background

There has been a growing interest in service evaluation and, in particular, evaluations that are controlled by users. Interest is especially evident among commissioners, who are accountable for purchasing effective and appropriate services and wish to demonstrate value for money and user satisfaction. Interest is also increasing among disabled people, who are demanding improved services and are looking for more effective ways of influencing service development.

There are a number of pioneering examples of service user groups leading or controlling evaluations. People First, a national organisation run by people with learning difficulties, has undertaken several service evaluations looking at services for people in group homes and at the quality of life of people recently resettled from long-stay hospitals.

Living Options Partnership has supported two projects where disabled people designed and carried out evaluations of community care services in their areas. This publication draws on the experience of these projects, which involved people with physical or sensory impairments aged between 16 and 65.

The underlying principles of user-led evaluation

Disabled people need to be active participants throughout the evaluation process. They need to be involved in identifying priority service issues and framing the questions which are at the heart of the evaluation. They also need to be involved in designing the evaluation, setting aims and objectives and deciding on the sample of disabled people who will be invited to take part.

Disabled people should be involved in selecting the methods to be used in collecting information for the evaluation, ensuring that they are accessible and capable of meeting their requirements. Interpretation, analysis and presentation of findings and recommendations all need to be undertaken by disabled people themselves. This means that there needs to be majority representation of disabled people in any committee or steering group set up to guide and manage the evaluation. This will help to prevent service agencies setting the terms of the evaluation and allowing their own perspectives and interests to influence both the process and outcomes of the evaluation.

Involvement and control by disabled people need to be maintained throughout, often using the local disability organisation as a base for the project. In this way, the experience of disabled people remains at the core of the evaluation, becoming available to inform decisions of both service commissioners and providers.

What can user-led evaluation achieve?

‘I know best about me, but they don’t listen to me’ Project participant.

User-led evaluation offers health, social services and other service agencies a detailed understanding of the experiences of service users, presented in a format that they can use. Such direct and detailed information on individuals’ and groups’ opinions, in an anonymous form, can be used to inform a needs-led approach to service development.

In the course of an evaluation, the disabled people involved can assess their own needs and indicate the service responses required to meet those needs. The impact of services currently being received can also be assessed and service outcomes identified. Information can be collected on needs assessment and care management processes; on specific service components of care packages and the ways in which staff work with disabled people.

As a result of the evaluation, changes may be brought about in service designs and the range of services on offer; in training and staff development; and in longer-term arrangements for evaluating services. The evaluation process itself is likely to result in disabled people feeling empowered. Service managers and practitioners are likely to gain a clear picture of the experiences that disabled people have as service users. In addition, new and better ways of working together in partnership often emerge, enabling problems and conflicts to be addressed in a constructive manner.

Evaluation outcomes

Living Options Partnership evaluation projects in Hammersmith & Fulham and in Shropshire produced evaluation reports34 detailing the users' opinions of community care assessment and packages of care. Disabled people have indicated how they wanted their needs met and put forward practical suggestions for alternative arrangements. A review has been offered to every individual whose experience of assessment and care management has been unsatisfactory, and a needs-led approach is now expected to be adopted by the statutory agencies. Independent advocacy is now offered at every review. Disabled people wanted higher-quality and more flexible services, with staff continuity. Individuals have experienced a change in their services and proposals for new developments are to be funded. For example, extending an independent living scheme to offer personal assistants instead of day care; funding access to independent advocacy; providing speech facilitation, as needed, at assessments and other key meetings. In addition, service specifications with the independent sector domiciliary care agencies are being reviewed on issues of communication, flexibility and quality.

In Hammersmith, the evaluation report has been used for training purposes. The Steering Group used the report as a training manual for care managers and called a half-day event for staff to discuss the issues and propose solutions. This is to be mirrored in the health service by using the evaluation as training for GPs.

The evaluation process has had an impact on people's attitudes.

In Shropshire, disabled people and managers at all levels of the health authority and social services had the chance to come together and talk to each other at two seminars. There can be no substitute for this sort of opportunity to learn at first hand the impact of services on the quality of life of individual disabled people. One of the project participants took two minutes to explain what having control over his own personal assistants means to him. For the first time I feel like an adult. This statement conveyed more about independent living than ten discussion papers could do.

In Hammersmith, some of the successes of the project were described as 'the meetings with users, senior management from health and social services and members of the social services committee'; 'The voice of the users was heard'; 'The inter-agency co-operation enabled the overcoming of issues of conflict'.

Both areas are committed to continuing the evaluation process and users involved in these evaluation pilots are joining groups of other disabled people to work with commissioners. In Shropshire the users group is linking with local disability organisations, and will form part of the User Involvement in Commissioning Group established with assistance from the National User Involvement Project.

In Hammersmith, the users involved in the project are forming a group to explore innovative solutions to the performance gaps identified by the evaluation. The group has merged with a consultation group organised by the local disability organisation, and regular feedback on services will be sought. The first meeting has already taken place with senior managers from health, social services and housing, together with councillors, seeking new ideas for individual service solutions.

Setting up a user-led evaluation

This chapter will consider:

- the planning process
- the implementation process
- making use of the evaluation
- continuous review.

The planning process

Practical arrangements for the evaluation

Time scales

Designing the evaluations and organising interviews and group discussions take up a great deal of time in the initial phases of the work. Time is also needed to identify the specific facilitation needs of disabled people involved in the evaluation and to put in place arrangements which will enable their effective participation. This applies particularly to people with language and communication difficulties. Experience shows that initial scheduling of evaluation projects can prove to be unrealistic as unexpected developments arise, and the processes involving disabled people at every stage simply take longer than originally anticipated. Building extra contingency time into evaluation schedules can provide the opportunity for reviewing and adjusting timetables.

Managing the evaluation

The individuals and organisations undertaking the evaluation need a formal structure, such as an evaluation steering group, to manage the evaluation exercise. Steering group members will take on a range of roles and responsibilities required to oversee and support the evaluation project and to facilitate the working of the group itself. When setting up the group, the following questions need to be asked. Who is line-managing the project? Who do users contact? Who is the group's chair? Who is the minute-taker? Who organises the meetings? Who manages the budget? What role does the funder have? Who 'opens the door' to contacts and information in social services and health? Who organises meetings with users and statutory authorities? What is the time commitment of all involved?

These roles and responsibilities need to be clear, in order to assist the evaluators in their task.

In order to preserve the user-led nature of the work, steering groups should aim for a minimum of 50 per cent members who are disabled people representing disability organisations, service users and disabled people who may use the services in future. Staff from statutory services also need to be involved, with senior staff playing their part in facilitating the implementation and review stages of the evaluation.

In both Living Options Partnership projects, steering groups included statutory service representatives from health, social services, housing and the voluntary sector (e.g. in Hammersmith & Fulham the Commission for Race Equality was represented). Initially, during the planning process, third- or fourth-tier officers were involved, but during the implementation phase it became important for second-tier officers to be directly involved in order to authorise access and agree processes. Their involvement enabled projects to influence both outcomes for users and achieve changes within their organisations to a significant degree.

Choosing the evaluators

At an early stage, decisions will need to be made about arrangements for engaging an evaluator or evaluators to undertake the work. Their knowledge and skills in evaluation will clearly be important, but so will their interpersonal skills and their ability to gain the trust and confidence of disabled people taking part in the evaluation. Bearing these requirements in mind, together with the importance of maintaining the independence of the evaluation, information can be sent to disability organisations or to individuals with evaluation expertise and personal knowledge of disability, inviting applications to undertake the evaluation. In Hammersmith, it was found that 'an external independent researcher with personal experience of disability/discrimination is helpful'.

Decisions will need to be made about the role that evaluators are expected to play in planning the evaluation. In some cases, steering groups may prefer to draw up their own evaluation proposals, expecting evaluators to advise merely on evaluation methods which are most appropriate and feasible. In other circumstances, evaluators may be expected to develop detailed evaluation proposals based on a simple brief articulated by the steering group. Both are effective ways of proceeding, each reflecting different preferences, skills and resources within evaluation steering groups.

When employing disabled people as evaluators, consideration will need to be given to their facilitation needs (e.g. transport, safety, personal assistance, administration support).

Resources required

Resources will vary, depending on whether the evaluation takes place in a rural or urban area, or involves individual interviews or group discussions. Resources are needed for the following:

- Facilitation. Funding for sign language and community language interpreters; for speech facilitators, including those able to speak community languages; for personal assistance to enable the interviews to be held independently if wanted separately from carers; and for group meetings.
- Transport. Funding the method that users prefer, including taxis, minicabs and social service transport.
- Payment. Funding provided to pay people for attending evaluation meetings, in recognition of disabled people's expertise and their contribution towards policy development.
- Venue. Independent, fully accessible, with adequate privacy.
- Childcare. To be arranged to suit individual needs.
- Information. In plain English, translated and on tape or in Braille.
- Outreach. To reach disabled people unlikely to be involved in existing disability groups (e.g. Black disabled people and disabled lesbians and gay men).

Designing the evaluation

As with any evaluation, decisions have to be made on:

- what is to be evaluated and why
- how the evaluations will be undertaken.

What is to be evaluated and why

Users may be interested in looking at long-established services, new provision or procedures and processes which affect their access to and use of the services (e.g. the needs assessment process). The focus chosen will be one that feels important to users themselves and may not coincide with the preoccupations of service providers. There may, for instance, be uncertainty and possibly suspicion among users about the declared merits of new service arrangements. There may be criticism emerging of particular aspects of a service or strong support for new ways of working which are as yet untested.

Regardless of the focus, it is at this point of the planning process when evaluation steering groups need to be clear about the purpose of the exercise. Discussions have to take place not only about what will be evaluated but also how the information gathered will be used to influence decisions made by service agencies on the future development of services.

How the evaluations will be undertaken

There are a wide range of methods that can be used to collect information. These include quantitative methods, using surveys, audits and highly structured interviews, which provide evidence on, for instance, the numbers of people saying or doing something. At the other end of the spectrum, qualitative methods may include case studies, semi-structured interviews and discussions, drama techniques and pictorial accounts. A rich and diverse collection of information, usually obtained from relatively small numbers of people, can be used to identify key issues and patterns emerging. The bibliography on page 22 contains references providing details of evaluation methods.

Depending on the evaluation to be undertaken, both quantitative and qualitative methods have a part to play in user-led evaluation. However, where users are being asked for detailed information about their experience and views of services, there are particular merits in choosing methods where users are most likely to feel involved and able to speak freely, without being confined to a narrow set of questions. Qualitative methods are likely to be most appropriate here, being especially useful in drawing out the views of people who may have communication difficulties or who are simply unused to being asked for their opinions about anything. It is also important that the methods chosen are understood by the users involved in planning the work and are able to be adopted by them in future evaluation exercises.

Living Options Partnership projects were being planned in 1993, just as the new community care arrangements were being implemented. In Shropshire and in Hammersmith & Fulham, evaluations focused on these new arrangements. Social services and health commissioners were eager to find out whether assessment and care management systems were working effectively, while disabled people's organisations were concerned to find out whether disabled people's needs were being met. Project design differed according to local circumstances and preferences.

The Shropshire project had the following aims and objectives for its evaluation:
Aims:

- To work with a group of disabled people who have been assessed since 1 April 1993 to evaluate the assessment process and the services offered. The project will specifically address the experiences of disabled people in rural areas and aim to improve procedures and services.

Objectives:

- To identify a group of disabled people who have experienced a comprehensive community care assessment since the implementation of community care in April 1993.
- To facilitate meetings of this group to gain their views about how assessment and care management processes might be improved or changed.
- To facilitate the group to make a presentation to social services, district councils and the health authority (which in Shropshire includes the family health service authority).
- To receive a response from the statutory agencies to the recommendations put forward by the project participants; what changes will be made and when they will be implemented.

- To continue the group as a consultative group.

Methods:

- Preliminary qualitative interviews were used as a way of involving users in the project, of eliciting their experience of community care and as an invitation to join in group evaluation meetings. These group meetings ranged from informal discussions to more structured methods enabling users to select the type of group they felt most comfortable in. A range of techniques were used, including art and drama.

The Hammersmith & Fulham project had the following aims and objectives for its evaluation.

Aims:

- To evaluate user satisfaction with the provision of community care packages and independent living schemes developed for disabled people aged between 18 and 64, living in the London Borough of Hammersmith & Fulham.

Objectives:

- To assess user satisfaction with the packages of care they have received.
- To seek the views of potential users of independent living arrangements in the borough to assist in appropriate service development.
- To find ways of representing the views of users in both individual and group capacities to service agencies.
- To provide information for purchasers, providers and users about how to increase the range of choices in their packages of care.

Methods:

A survey was undertaken, using semi-structured questionnaires and individual interviews. A self rating system was used to measure people's level of satisfaction with their assessments and packages of care, based on people's own definitions of their needs.

The implementation process

The sample

Selection

The numbers and types of people involved in the evaluation will need to match the aims of the evaluation, the funding available and what is achievable. All users of a service may be part of the evaluation, making allowances for those who do not wish to participate. Alternatively, it may be necessary to select a sample which is valid and representative of a wider group of users. It may be important to involve potential users. This is particularly significant with Black disabled people who may find existing services inappropriate or insensitive, or may not have access to the information to even consider using the service. To gain a full evaluation of services, ways of contacting potential users who are excluded or choose not to include themselves need to be found. Outreach work to community organisations, religious and cultural organisations is needed to get in touch with Black disabled people and other marginalised groups so that their opinions can be included in the evaluation process.

A great deal of consideration needs to be given to selecting the sample, in order to achieve a rich and useful assessment of any service. If, for example, users' views of a district nursing service were the focus of an evaluation, the opinions of people who are hospitalised due to pressure sores or admitted to residential care because of the limitations of community services, may be essential to illustrate how the service could be improved.

In Shropshire and in Hammersmith & Fulham, the sample included only those disabled people who had had complex assessments and received packages of care since the introduction of community care in April 1993. This sample concentrated the attention of the service agencies on the first disabled people to experience the changed procedures for community care. There were, however, several disadvantages. The sample size was relatively small and so information was limited, but it was accepted by service agencies as a strong indication of users' opinions. As Black disabled people are under-represented as users of statutory services, very little information could be gathered on their experience of services. This was acknowledged in Hammersmith & Fulham as a limitation and was highlighted as a need for further evaluation.

Making contact with the sample

It is essential for some preparatory work within the statutory agencies to take place to gain staff support for the evaluation. At first it may be seen by staff as threatening, but a good flow of information about the purpose and process of the evaluation will assist the work. Statutory agency staff will need to identify the individuals within the sample and an initial letter will need to be sent out to request their permission for their names and contact details to be forwarded to the evaluators.

Once the sample group is known and adjusted as necessary for statistical accuracy, the active support of service agency staff is essential. Care managers or home-care organisers, day centre managers or district nurses are holders of accurate information on addresses, hospital admissions, availability and language or communication needs. In addition, because of their position of power, their attitude towards the evaluation can be the deciding factor for service users who fear that confidentiality might not be guaranteed. These hidden factors can affect the number of respondents. Representatives of statutory agencies on steering groups have an important role in preparing staff in order to reduce these barriers to the evaluation.

Statutory agencies can be the link to providing speech facilitation and language interpreters and, if needed, the link to speech facilitation in other languages. Access to these services is needed for the full participation of the sample group.

Collecting the information

The information is likely to be gathered through a combination of individual interviews and discussion groups. These are valuable ways of gaining direct information and people's experience, both on a one-to-one basis and through encouragement from others in a group setting.

A number of issues can arise in the process of gathering information, relating to confidentiality within the evaluation, and difficulties may emerge in the course of individual interviews and group discussions.

Confidentiality

There is an overriding need for the disabled people to trust the evaluators and others involved in the evaluation to maintain confidentiality about their experiences of services. Evaluators should:

- identify themselves as independent of statutory agencies and working to a code of practice which ensures confidentiality.
- guarantee that all published information will be anonymous and that, where an individual could still be identified, their information would be either removed or disguised.
- provide written commitments from chief executives of health commissions and directors of social services that any reprisal or reduction in service experienced by a member of the sample as a result of their participation would be investigated by them personally and resolved.
- agree confidentiality rules with all involved in group discussions taking place as part of the evaluation.

Issues that may arise from individual interviews

During the course of an interview it may become evident that the disabled person is in danger, or is receiving abuse, or is expressing discriminatory views about service providers. The interviews may take a long time to complete, and disabled people's experience of community care may be very negative. Mechanisms need to be put in place to deal with these issues.

Evaluation steering groups should:

- agree that all interviews take place using a code of practice such as that of the British Association of Counselling. This would be a guide for the evaluators to judge how to deal with situations.
- agree that the evaluation will take place within the equal opportunities policy of the agencies represented.
- identify emergency contact numbers for health and social services for the evaluators to use, where appropriate.
- draw up a mechanism for the statutory agencies to respond to issues of concern if the disabled person wishes to raise them.
- allow adequate time for the interviews within the scheduling.
- provide regular supervision/support for the evaluators to enable them to remain effective.

In Shropshire, the initial contact interviews with project participants proved to be more lengthy than had been originally intended. This was because many people had plenty of 'off-loading' to do before there was any discussion of the project itself. There was also the difficulty, on occasions, of getting past the carer. It was essential that the project participants were able to see positive action from their efforts. The feeling that 'nothing ever changes' is powerful and often based on some negative experience. There was also a feeling that raising any comment or complaint might endanger existing rights to services. The project began the process of breaking down these barriers of mistrust felt by disabled people, but this is a process that cannot be achieved overnight.

In Hammersmith & Fulham it was found that the complexity of interviewing service-users with communication and cognitive difficulties had been a learning process for all those involved in the project.

Issues that may arise from group discussions

Group discussions provide the opportunity for users to identify issues of common concern and propose alternative ways of providing services that meet their needs. The evaluators have an important role in encouraging participation, as users may feel that their opinions will not be valued. 'What is the point of me saying anything - I've got nothing worth listening to' Project participant.

The evaluators have to assist the group to move beyond their individual experiences and relate these to wider service provision issues. However, every attempt must be made by the evaluators to guard against suggesting, steering or promoting their own solutions at this point, especially where the aim of the project is to enable users to control the outcome of the evaluation. The success or failure of the work can hinge on the importance of enabling the users' opinions to remain central at this stage.

Other issues arising include the following:

- Individuals have no immediate group identity and can take time to operate as a group.
- For many people this will be their first experience of attending a meeting, and they will require time to participate fully.

- The discussion venue may be far from people's homes and the distance can be too great for people to travel - especially in rural areas.
- Transport difficulties and, sometimes, levels of tiredness can leave little time for group discussion, despite people's determination to express their views.
- Particular attention needs to be focused on groups often excluded from provision (e.g. disabled lesbians and gay men and Black disabled people) so that they are included in the process.

The evaluators should:

- stress the importance of the work, indicating how users' views will be used by statutory agencies to bring about positive change.
- allow time for the group to meet informally and slowly build a style of group co-operation and inclusion.
- offer alternative types of group meetings which people may be more interested to attend (e.g. drama or cartoon drawing to express opinions in a non-verbal way; separate meetings for disabled lesbians and gay men).

Analysis

The information gathered during individual interviews and group discussions is grouped and collated by the evaluators. This is then distributed to everyone in the sample, in accessible formats. Further contact is made to encourage people to attend a meeting to analyse the information together and identify group solutions to the service problems that they have experienced. Alternative ways of offering comments and solutions are organised for those unable to attend meetings.

Evaluation group meeting

This meeting is arranged to analyse information gathered and to decide on what action the group wishes to take. These meetings should be open only to disabled people and evaluators, in order to maintain control of the information by the users. Meetings provide opportunities for people to gain information from each other, to discuss common themes and agree priorities for change. Aspects of services and assessment processes which have caused the greatest difficulties can be analysed, and group suggestions for improvements or alternative approaches can be agreed.

Disabled people's experience and expertise on specific service issues are distilled and a needs-led approach devised by them as an alternative to current practice. This is where the unique value of user-led evaluation becomes apparent.

Service solutions are proposed in a series of recommendations. These recommendations for change form an important part of the evaluation report which will be presented by disabled people to service agencies.

In Hammersmith & Fulham the evaluation group chose to focus on ways to:

- improve the assessment process by increasing user involvement, control and flexibility.
- provide continuing user feedback/evaluation by setting up joint forums (of users, practitioners, planners).
- establish new services such as personal assistance and extend access to advocacy and speech therapy.

In Shropshire, users felt that the 15 areas of 'need' outlined on the current assessment form were too fragmented. They defined their own model of community care assessment which encompassed all the essential elements for them to achieve a reasonable quality of life. They called this the needs-led flower model of assessment. At its centre was the need for rights, information and advice - considered essential for the user of community care services to be able to access the other four areas that go to make up a quality of life. These four areas are:

- Physical well-being, which includes needs such as personal care, medical health, domestic tasks and care issues.
- Getting around, which consists of physical ability, transport, mobility and communication.
- Emotional well-being, which consists of mental health, financial affairs, leisure opportunities and personal fulfilment.
- Living space, consisting of safety issues and suitable accommodation.

From the user perspective all these areas, though distinct, are interrelated. The users produced a full document citing people's evaluation of services and proposing group solutions to each point made.

Making use of the evaluation

User-led feedback

This is the point when disabled people present their findings and recommendations to officers and/or authority members responsible for the services/processes being evaluated.

Issues that can arise from evaluation feedback meetings include the following.

- Statutory representatives may be very concerned about what the evaluation might say. Respective members of the steering group can assist their organisations by informing them fully about the value of the evaluation before the meeting. This helps to gain the maximum openness from all participants.
- Disabled people can find the prospect threatening as they may be individually identified as participants, even though the evaluation results have been anonymised. Assistance with presentation skills and assertion skills before the meeting should be offered.

If disabled people have been actively involved in the process of evaluation there will be an expectation that services will improve both individually and for other disabled people. The participants will have gained a great deal of information about community care and will have a clear sense of their needs and how these can be met. This empowerment of disabled people is an unexpected outcome of the evaluation, and if developed with the service agencies, will provide a strong partnership for future service development.

In Shropshire a seminar was organised for the group feedback meeting. Representatives from the statutory agencies, who were able to make decisions about services, were invited. The seminar was a powerful experience for the statutory agencies because it was led by disabled people talking about how community care affected their lives. The recommendations put forward by the project participants at the group feedback meeting certainly made an impact.

In Hammersmith & Fulham, service agencies said that 'one of the successes of the project was the meetings held between users, senior management from health and social services and members of social services committee'. Despite initial concerns from officers, the face-to-face meeting between individuals had proved a catalyst for change.

Responses from agencies

This is a powerful and important stage in the evaluation, as it is the time when statutory agencies acknowledge the value of the users' evaluation and respond, showing what action they propose to take.

In Hammersmith & Fulham, a formal meeting for a response from agencies was delayed for several months. In that period, statutory agencies had decided to take action on a number of initiatives as a result of the users' feedback meeting and wanted to complete arrangements before the formal response meeting. These included decisions to:

- purchase speech facilitation services, making them available as necessary at any assessment.
- hold a workshop for all care managers to seek solutions to problems identified by the evaluation.
- extend the contract of the independent evaluator to undertake visits of all of the sample group as soon as possible. This was to discuss their needs further and for them to identify how they would want to have these needs met.

There would be a further meeting between the evaluator/facilitator, the user and their care manager when a needs-led assessment would take place and the package of care would be adjusted as requested. (In practice, the users were so clear about their needs as a result of participating in the evaluation, and the care managers were highly committed to the work, some reviews had already taken place). A meeting was organised between commissioners and providers to feedback findings from the evaluation and present the final draft of the project report.

These developments preceded a final meeting between disabled people, councillors and service agencies, where agencies were able to report on the progress of the developments and examine other recommendations of the evaluation. Because of the openness of the statutory agencies to the users' views, the final meeting was used by service agencies as a working event. Ways of jointly reorienting services to make them more responsive to the evaluation findings were sought by both health and social services.

In Shropshire, the director of social services, the chief executive of the health authority and other key organisations organised a follow-up seminar three months later. The recommendations were taken very seriously and every effort was made to give clear, realistic answers. Responses ranged from full acceptance and commitment to implementation, to outlining work that was already taking place, to a cautious acceptance of some recommendations because their implementation had resource implications.

Continuous review

Evaluations are a valuable way of learning about a process or service at a point in time. Action can be taken as a result, and it will have been a useful process. While one-off evaluations are undoubtedly worthwhile, it is also worth considering ways of building continuing evaluation into service development strategies. This will build on commitment developed during any one-off evaluation. Commitment and involvement of service staff will also need to be maintained and demonstrated throughout successive evaluations. Resources will need to continue to be made available so that disabled people can maintain full involvement.

In Shropshire after the Agency Response Seminar, the project participants were contacted again and visited individually. They were asked whether they wished to continue the group and in what form. Nearly everyone wanted to continue as a group, and arrangements have been made for the users concerned to participate in a ‘User Involvement in Commissioning Group’.

In Hammersmith & Fulham it is hoped that a ‘feedback loop’ will be set in place, to enable the joint consultative and evaluative process to continue after the end of the project. Located within the joint planning system, this would enable evaluation to become an integral part of the planning and service development process.

Conclusions

With increasing competition among providers and the growing expectation for quality from disabled people, there is an urgent need to know if services are effective. There is a legislative requirement to involve service users in assessments and in community care planning, but statutory agencies have often found that this has been tokenistic. User-led evaluation has proved a surprisingly positive way of users improving the quality of their individual services, and finding ways of developing new services that are more flexible and empowering.

Initially, service agencies may express caution and concern. ‘The preparation for community care implementation prior to April 1993 has led us to believe that when you really allow users a voice, it is a shock to the system for professionals.’ Social Services Assistant Director. However, once the evaluation gets under way the value of the work begins to emerge and positive comments are made. ‘Users should be our allies and partners’, and ‘The users’ voice comes through clearly’. Defensiveness breaks down and dialogue really does take place.

The model outlined in this document could be applied to measuring the effectiveness of many different service aspects. In the long term, it would be possible for disabled people to define the quality measures that they think are most important for the services that they use. These would become the benchmark by which they could assess the quality of services and monitor on a regular basis. These quality measures might be incorporated into inspection and audit processes, where they could be used by lay assessors and others.

User-led evaluation has proved to be a creative way of distilling user views and providing answers to the question asked by commissioners, ‘Is the money I am spending on these services making a positive difference to people’s lives?’. User-led evaluation is a new way of building a working partnership between commissioners, providers and disabled people, and is offering the information needed to develop a needs-led approach to service development.

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Back Cover

When disabled people take the lead in evaluating community care, they produce valuable insights into service effectiveness and creative suggestions for improving services. Real changes result when community care agencies listen to and act on disabled people's assessment of the services on offer.

This publication discusses the benefits and practicalities of user-led evaluations and includes case studies on two Living Options Partnership projects where disabled people successfully evaluated community care services. It is essential reading for all purchasers and providers in health and social services and for organisations of disabled people.