Have We Got Views for You

User Evaluation of Case Management

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This report was commissioned by The Sainsbury Centre for Mental Health. It aims to provide an independent view, from the user perspective, of the quality of care delivered by the case management teams involved in The Sainsbury Centre Case Management Project. Case management is a way of delivering care and support to people with mental health problems, which has been the focus of considerable research effort at The Sainsbury Centre. References for this work can be found in the Appendix.

The report was researched and written by The Sainsbury Centre User Group. The Group consists of users from all over England and Wales. They meet regularly with managers from The Sainsbury Centre, to offer their views on the work of the Centre, and to discuss more general issues of concern. The fact that those researching this project were also users was important, as it was felt that the service users being interviewed would express their views more freely to fellow users.

Whilst The Centre provided funding, support in designing and implementing the project, and published the report, final editorial control remained with the report's authors.

The Sainsbury Centre would particularly like to acknowledge the very considerable achievements of the project. The user researchers worked long and hard, and with great professionalism, to produce it. Their findings are a valuable additional resource to those wishing to implement case management within a mental health service.

Acknowledgements

We would like to acknowledge the invaluable contribution of Vida Field in assisting us in integrating and writing up the data.

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1 Introduction

The Sainsbury Centre for Mental Health Case Management Project (funded by the Department of Health, the Gatsby Charitable Foundation and the participating districts) proposed a co-ordinated approach to the provision of services to a group of people with multiple disadvantages. One of the concerns of service users has been to establish whether, despite the implications of its title, this model of care is able to live up to its increasing claims to be a client-centred approach. This report describes an exciting new venture - an independent review of the views of recipients of the case management service, by mental health service users from outside the service.

When The Sainsbury Centre for Mental Health first developed and promoted its views of case management (Towards Co-ordinated Care, Clifford et al. 1988), the views of service users were largely overlooked. This fact is highlighted by the lack of attention given to the meanings of the labels used by mental health services. Case management, a radical new initiative in mental health care has, at its core, the notion that people with severe mental health problems are 'cases' to be managed. This led to The Sainsbury Centre's first efforts to bring in a user perspective. A group of users from around the country began to meet together to produce a response to Towards Co-ordinated Care. This new document, Whose Service Is It Anyway?, showed, as had the activities of various user groups, that users could no longer be perceived as passive recipients of service and had strong views on the sorts of services they wanted. The Sainsbury Centre User Group provided one point of reference for the Case Management Project as the services and the research developed.

What is Case Management?

There are different models of case management and much has been written about its theory and practice (Onyett, 1992). This report will only look at the way it was developed in The Sainsbury Centre project.

Essentially, case management is a system of service delivery designed to provide care and support for people with severe and long-term mental health problems, who would otherwise be at risk of losing contact with services. Case management recognises that these people risk being unable to cope with the personal, social, financial and other difficulties which arise either as a result of their mental health problems (or the treatment for them), or the unemployment, poverty and stigma attached to mental health problems (Ryan et al. 1991).

Each case manager carries a small caseload of about ten users, in order to be able to give a lot of time to each client. They are organised in specialist teams, each with a case management team leader. Every person accepted by the case management service has their own case manager. He or she is responsible for working with them to develop their strengths and helping them sort out areas of difficulty. This is much more than just ensuring that various bits of service are in place (eg attendance at a day centre or out patient appointments). A case manager will work with someone, help them to identify their preferred way of spending the day, then actively seek out possibilities (eg sheltered employment, swimming, adult education classes) and help her/him to arrange it. They will also accompany her/him, if that is what the user wants. This sort of help extends into all the areas that are important to the service user and does not focus narrowly on traditional 'psychiatric' treatment, such as medication.
The Sainsbury Centre Case Management Project was established in four health districts: Nottingham, Bromsgrove and Redditch, Guy's and North Southwark, and Hastings and Rother. An integral part of the project was an evaluation of the process and outcome of the case management service. The researchers attached to the teams included measures of user satisfaction in their evaluation.

Why This Work?

The Case Management Project, begun in 1989, was due to finish in September 1993 and The Sainsbury Centre was planning a conference to describe some of the findings and to promote its ideas of client-centred case management. A previous Sainsbury Centre conference had no scheduled input from service users and they had arranged a spontaneous workshop on the day. Users present at that conference had expressed some doubts about the limitations and control which seemed to be implied by case management and about how far users' wishes were valued by the case managers. The manager of The Sainsbury Centre Case Management Project had maintained ongoing contact with The Sainsbury Centre User Group since that time and all were resolved that user issues should feature more prominently on the agenda. It was acknowledged that the users receiving case management had multiple disadvantages and would find it impossible at this stage to present their views before a large audience, although this was not ruled out as an ultimate aim. Instead of their perspective being mediated by professionals involved in service delivery or research, it was proposed that it should be presented by other users. The National Steering Group of the Case Management Project agreed, therefore, to fund a user-led evaluation of the case management service which would be presented at the conference, but which would also have wider import as an innovative way of measuring the impact and quality of a service from the users’ perspective. It was important that this evaluation was seen as a project worth funding in its own right and that the user researchers were paid for their work.

It is not unusual now for service users to present a user perspective on mental health issues, nor for users to run workshops and to be part of presentations on services they are involved in. The growth of the user movement and the active campaigning, advocacy and development work of local and national groups, has ensured that users are now considered legitimate participants in planning, consultation and service delivery, at least in some areas. At a local level, users are considered the best people to find out what other users really think of the service. Measures of user satisfaction are routinely incorporated into service evaluations but are often criticised for showing such high satisfaction as to be unhelpful. It is much less common for users to be commissioned to conduct an evaluation themselves. Perhaps this is a welcome sign that research organisations are acknowledging the skills of service users and the validity of their approach to evaluation. There was a missionary aspect to this piece of work which aimed to get other organisations to see its usefulness and do something similar. It was part of the process of redefining users as thinking, reflecting people who are partners in the process of care.

The Case for User-Led Research

It was strongly believed that users, who can demonstrate their common experience with other users, could get at the truth much better because they could persuade other users of their independence from the service. It is not the wish of this report to discredit other researchers but simply to assert the value of user-led research. In particular, the issue of independence from the service provider is very difficult for non-user researchers. Their background, presentation and
links with service agencies make it difficult for users to believe that their views will not get back to those who provide the service directly. They then fear that their service might be withdrawn or that they will be made to suffer for their criticism. Service users also feel a sense of responsibility to their workers and are reluctant to do anything which might get their worker into trouble, or might affect the funding of the service. This latter consideration is a factor for whoever undertakes the research, but the independence of user researchers should ensure that they have more chance of getting at the truth of what people think. The perceptions it seeks are those that users would want to tell each other, not what they have been told is good for them. If there is then a positive view of the service, it increases the credibility of that response.

The Sainsbury Centre User Group was keen to take on this piece of work because the case management services were pilot projects. If this style of service was to become more widespread they wanted to be sure it was good, and that the best models would be disseminated. Members of the group had been suspicious of case management's ability to deliver what it claimed. They were also worried about how empowering it was - it could seem controlling and patronising - but they hoped that some of those views had been taken on board. The group was also keen to show that user-led evaluations could provide useful information about services. An additional question, which was increasingly preoccupying users, was whether co-operation could get services delivered without compulsion. Was case management a realistic alternative to community treatment orders or other forms of compulsory supervision in the community? It is difficult for non-users to comprehend fully just how threatening and offensive the discussions about community treatment are to users, especially because of the underlying attitudes they betray. The interest in case management springs partly from the hope that it is a manifestation of a different approach to users, which builds on their strengths and works with them to prevent crises.

Underlying this evaluation, then, were the two contrasting attitudes - the initial impression that case management in the past had not seemed to value its users and had the potential to be very paternalistic and, on the other hand, the hope that this was a new approach which would deliver what users wanted by working with them, not doing to them. The researchers were particularly keen that the evaluation should show what users were really saying about these issues - not what they had been told was good. Users were to be seen as partners in the process of evaluating, as thinking, reflecting people whose perceptions were valid judgements of the services.

How Was the Exercise Done?

The main part of the information gathering process was through individual interviews with case management clients, using a questionnaire as a guide but also allowing for the collection of more discursive comments. To back up the interviews there were also group discussions in each of the districts. The questionnaire format was used because it was easier to then compare and code answers. Ideally, if time had allowed, it would have been better to develop the content of the questionnaire through prior consultation with users of case management, so that the key issues identified by them would be directly reflected in the questionnaire. To overcome the limitations of the survey method, group discussions were used to explore further the issues which were most important to the users. The questionnaires and discussion groups provided a check on each other and helped to build a more three-dimensional picture. Four users were commissioned to do the work and each visited two sites in different combinations. Each researcher avoided the district nearest to their home district.

A questionnaire was initially designed by The Sainsbury Centre project staff and the user consultants redesigned it in the light of what it would mean to users. They extended it to try and
get at the impact of case management in a user's life. Any bias towards positive answers was
removed, the professional viewpoint was altered and the language simplified and made more
straightforward. (See Appendix for a copy of the questionnaire.)

Once the questionnaire was finalised, the user researchers contacted each case management
service and requested that they set up individual interviews with willing service users. They were
asked to stress the confidentiality of the interviews, the fact that case managers would not be
present, that the interviewers were themselves service users and that there was no pressure on
anyone to take part. They were also asked to provide the opportunity for a group discussion in
settings where service users met together. The case management teams were very willing to do
this and, despite one or two administrative failures, the project was able to go ahead in all four
districts. The researchers also felt that it would be useful to feed back in general terms to the case
management teams and to have a discussion with them.

What We Found

23 individual interviews were conducted in the four districts as follows:

Hastings and Rother  4
Guy's and North Southwark  4
Nottingham             12
Bromsgrove and Redditch  3

Eight of the interviewees were female, 15 were male and their ages covered the whole adult range.

It proved difficult to find space for a group in Hastings so a rather more informal chat took place
with the users present at a local day centre. One group discussion was held in Redditch, one in
North Southwark and four in Nottingham. In two of the Nottingham groups not everyone was in
receipt of case management. The Nottingham project had four case management teams and,
therefore, a much larger number of clients who could potentially be interviewed. Only one person
refused to go ahead with a previously agreed interview. All but three of the interviews were held
in the interviewee's own home and the case managers were not present at any. The researchers
always introduced themselves as users and gave some of their own experiences of hospital and
other services to help put interviewees at their ease and to give them a dear sense of where the
interviewers' loyalties and sympathies lay.

The results of the interviews are presented as a whole, as there were no identifiable differences
between sites on the answers to individual questions. Information from the group discussions and
interviews have been combined to show the general themes which arose.

What Did the Interviews Tell Us?

It was dear in both the individual and group interviews that the users of case management did not
feel pressurised to take part and many expressed their enjoyment of the experience. They said
they felt the user researchers really understood what they were saying and they found it easy to
talk to them. The researchers felt that the interviewees were not inhibited in expressing their
views and none seemed to fear that they would be scapegoated if they were critical.
Respondents were on the whole positive about their experience of case management but this did not mean that they were uncritically satisfied with everything. There were 22 questions which could have elicited a totally negative response and it is important to note that while three people gave no negative or critical responses (and two people gave as many as six critical responses) the majority (16) gave one, two or three responses showing dissatisfaction, out of the possible total of 22. Users were discriminating in their responses and dear about what they did and did not like, and what had improved and what had not. They were prepared to say that some things had not worked and this gives increased weight to the positive comments.

Satisfaction with case management

People's overall feelings about case management were sought through a question on what they liked and disliked about it. Some people gave more than one answer but the areas of impact were similar for many people. 12 liked the accessibility of the case manager, eleven liked the involvement in decision making and ten liked the friendliness of their case manager. Nine people disliked changes in case manager, five thought they had too much contact and three thought they had too little contact with the case manager. The responses to this general question very much concentrated on the relationship with the individual case managers and closely mirror the aims of the case management project. The criticisms did not seemed to be about the aims of case management but its implementation.

Involvement in care plan

The task of case management is to improve people's lives and functioning in all the areas where they seemed to be problems or deficiencies. In an ideal world users would be equal partners in the development of the care plan and would be involved in setting priorities and goals. A series of questions designed to check the level of user involvement in this area of decision-making showed that most users felt that they had a major input. 19 users felt they were involved in discussions about what they wanted, although three felt they were not involved. 12 felt that both themselves and the care manager decided what they would talk about, but four felt that the case manager made that decision. All interviewees felt that they could request a meeting with their care manager whenever they wanted one, and that their request would be met, although ten thought they would have to wait. 15 were satisfied with the contact they had with their case manager, two were not and five were not sure. 17 had set goals with their case manager, four had not and two did not respond to that question. Of these 17, three said they were not involved in setting the goals, six felt they set the goals and eight felt they were both involved. In order to check how this worked in practice, interviewees were asked what happened if they wanted to do something and if they did not want to do something.

Overall, what emerged was that most people feel that they have some control over decisions about what happens to them and that they are involved in the decision-making process. Very few feel that the case manager is making decisions for them or controlling what they can do. This is in marked contrast to what users say about traditional mental health services, where they feel that they are neither consulted, listened to or given information.
Access to services

If case management is working well then the users should be put in contact with a range of services which would provide opportunities for improving their lives. Of course case management cannot put people in touch with services that do not exist, nor can it ensure that those which do exist are valued and high quality. Within those constraints, however, there is much that good coordination can achieve. 15 of the people interviewed thought they were receiving the services they should be receiving, four did not and four did not know. Ten people were receiving services they would rather not have. The latter were largely accounted for by dissatisfaction with the way medication was dealt with, by the day services people attended or by the fact that they sometimes have to go into hospital. 14 respondents said that the case manager checked that they were receiving the agreed service, three said they did not and four did not know.

Case management, as a service in itself, was thought to be different from other services in four major ways: accessibility (18 respondents), helping with practical problems (15), involvement with the family (8) and developing outside activities (9). It can be seen, therefore, to be addressing many of the issues of major concern for users as faults in traditional services.

Case management and advice

Case managers build relationships with their clients and see them regularly but they are not the only people to whom clients can turn. 17 of the interviewees said they would contact their case manager if they were upset and 15 of them would turn to the case manager with a problem about their benefits. However both the GP (9 responses) and the psychiatrist (7) were seen as appropriate people with whom to discuss medication, as well as the case manager (8).

Quality of life

Overall, people reported an improvement in the quality of their lives since they had entered the case management scheme.

Over half reported improvements in their basic living situation, their leisure activities and their personal safety. A disappointingly smaller number reported increased quality of life in relationships with other people and in relation to work.

The individual interviews seemed to show a high level of satisfaction with, case management and an understanding of the basic issues. Not all the negative responses were from one or two

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<th>User wants to do something</th>
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<td>CM agree/discuss</td>
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<td>CM disagree/discuss</td>
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disenchanted clients, those who were very satisfied still found things which were not to their liking, and those who appeared very disenchanted nonetheless found things to praise. This gives these findings extra weight. The findings of the individual interviews were supported by the group discussions.
2 Major Themes in Case Management

Common themes emerged from the interviews and group discussions regarding what people most valued about case management. Although there were some differences of emphasis between the different sites (one site seemed to have concentrated more on housing, for example, and another on occupation), there was generally a large measure of agreement between individuals and the different groups about how case management had managed to make a difference in people's lives.

Relationships

'I think she likes me.'

Central to the notion of case management as implemented in The Sainsbury Centre project is the relationship between the case manager and the client. In the brokerage model of case management, the case or care manager arranges a package of care for the client and monitors its implementation. The Sainsbury Centre model is often called the clinical model, not because the case manager is a psychotherapist or spends a lot of time engaged in heavy one-to-one therapy, but because the relationship between the client and the case manager is the cornerstone of the care. The case manager also makes all the other service arrangements, but the reason case management is successful is because it is in the context of a meaningful relationship - one which allows potential for development. This was the overwhelming message from the interviews and the group discussions. What the majority of people valued most of all was the relationship with the case manager. This should not surprise anyone, especially in the light of what service users have long been saying about 'wanting to be listened to', and about needing to be 'partners in their own care'. Not everyone felt so enthusiastic, of course, but for the majority the case manager was a friend.

The relationship between case manager and user was viewed realistically by users:

'I can't talk to him about everything, but most things.'

'The case manager is my friend but I can't tell her everything.'

Idealising the case manager would, ultimately, not be a helpful experience and the users were aware of the responsibilities of the case manager:

'She doesn't let me get away with anything-she's not too soft.'

People were aware that they had serious problems in the past and that there was always a danger that things could start going wrong again. They saw the case manager as the person who would tell them if they were avoiding the things they needed to avoid, or who would help them to face difficult issues which, if not faced, could lead to practical or emotional difficulties. It was not just by being friendly that the case manager helped to keep them out of hospital. It was also by keeping them to agreements, by providing the opportunities to change things and by being professionally reliable. This was engagement in the fullest sense.
Empowerment/Choice

At first, service users were concerned that, although the clinical model of case management might provide lots of services and be readily available, it might also impose the case manager’s view on the service user. There was a real fear that, from the best of motives, case managers would wish to control or protect people whom they saw as seriously damaged. The case manager might not be open to the possibility that users could want to make their own choices. Interestingly, this was the fear of those users in Nottingham who joined the group discussion on the hospital ward and who were about to join the case management scheme. They were torn between the wish to get away from the control of services and the acknowledgement of the usefulness of someone to help them to sort out their benefits and accommodation.

Those who had already experienced case management mostly felt much more positive about the way they had been listened to and allowed to make choices. They felt valued as people with skills and abilities:

‘We are much more alive. You would not recognise us as the people we were before.’

This group of people were describing how they had started to get involved in setting up a drop-in cafe for users and now felt able to take on other ventures.

People also felt that the case manager listened and allowed them to proceed at their own pace. One woman felt that after previous episodes in hospital she had been pushed back into full-time work and this had caused her to break down again. Her case manager had not pressurised her but had encouraged her to develop the things she felt able to do, so that she now felt more confident about considering a return to work. Others felt that the case manager had taken an interest in their hobbies, where as previously people had dismissed them as bizarre or unhelpful and (for example, by expressing concern that ‘collecting things’ would lead to untidiness and clutter):

‘My case manager backs me up in what I want to do.’

There was a strong sense that by allowing people gradually to build up to taking their own decisions - by letting people take back control over their actions - case managers were helping people back into the world and relieving not only their sense of isolation but their sense of shame.

Practical Help

A constant theme in users’ writings has been the contribution that practical matters (for example, housing and finance) can make to mental health, both in terms of them precipitating crisis, and in being adversely affected by hospital admission. If case management was to make a real contribution to people’s lives, the case manager was going to have to undertake practical work. It is not enough for the case manager simply to ‘get housing’ for someone. The user must be able to keep their home and feel secure in it, which implies an ongoing commitment to helping with practical things, not just a one-off intervention:

‘The case manager mended my front door, which was really good.’

One person described how the case manager was helping to sort out difficulties caused by flat-sharing. Several had been able to find and-move into new accommodation with help from the case
manager. One man spoke eloquently of having his own home for the first time, and being able to invite people there instead of always feeling a burden to others. The case manager had enabled him to cope with moving and learning new skills.

The other major area of practical help was with finance, both in the claiming of benefits and in managing their personal finances:

'She helps me with benefits.
I now have more money and I can pay my bills.'

One man with a physical disability had been helped to claim Attendance Allowance and this had transformed his life with his parents.

Case managers advocated for their clients not only with DSS and housing providers but also with GPs and psychiatrists, where medication was concerned, and with other doctors about medical conditions.

The relief of knowing that there was someone available to sort out these practical issues was a major factor in helping people to keep well and out of hospital. Knowing that the case manager was reliable, readily available, willing to tackle a problem about a bill or a difficult negotiation about medication, and provide a therapeutic listening ear, gave people the confidence to tackle the challenges of living in the community.

Use of Leisure Time

Case management faces a real challenge in helping people to integrate into ordinary leisure facilities. One of the principles of community care is that people with mental health problems can use the same valued facilities in the community as the rest of the population, but this rarely happens. Issues of poverty, lack of confidence and rejection by other people are major obstacles. However, people in the case management projects felt that they had been enabled to make much better and more enjoyable use of their time. Case managers had met people in pubs and cafes and enabled small groups of users to meet each other in ordinary venues. Some people had been able to go swimming and bowling. The budget available to the case managers had been used to pay for course fees for further education. There was a strong sense that, finally, people were able to join in the ordinary things of life from which they had been excluded for so long.

Family Relationships

In discussion groups, people spontaneously expressed pleasure that relationships with their families had been much improved. In one case a man felt that his case manager had a better relationship with his parents than with him, but that this was acceptable as he had a good relationship with his CPN. Not only did case managers explain things to families and work directly with them, sometimes they also helped by arranging new accommodation and helping people gain independence, which enabled them to relate to their families in new and more equal ways. Sometimes respecting confidentiality was the most important need. One woman, whose previous workers had not respected her wishes not to tell her parents things, was pleased that she could trust her worker not to break her confidence.
What Did the Users Dislike?

There were three areas of real dissatisfaction which emerged from the discussions: day time activities, hospital admission and medication. Despite the very real improvements for many people, there was still a shortage of valued activities in the community. The day facilities were described as boring, yet people found themselves isolated if they did not use them. We heard of many imaginative solutions to this problem but clearly they did not solve all people's needs. In particular, those who wanted to work had mostly been unsuccessful and industrial therapy was not a popular alternative. There was a limit to what case managers were able to achieve in the absence of facilities in the community and there seemed to be a limit on the amount of integration into normal facilities achieved so far.

It is not unusual to find that service users dislike hospital admissions. While many thought their case manager kept them out of hospital; some felt more ambivalent about their case manager having persuaded them to go into hospital. One man said that his case manager did not keep him out of hospital, but felt this was because 'when he got bad, he got very bad' and he did not, therefore, expect the case manager to be able to keep him out.

Medication is another difficult issue for users, for very obvious reasons (Breggin, 1991). Nobody expressed the wish to give up their medication altogether but many felt unhappy with the side-effects and felt it could be better. Going to the depot clinic was also unpopular and the continued existence of such an alienating practice seemed to fit badly with the ethos of case management.

To quite a large extent, these dissatisfactions were beyond the scope of case management, but there were other issues related directly to the case management projects. Users were very angry that the service might be taken away:

'Isn't it just what always happens, you get used to something then they take it away.'

They were apprehensive that funding would stop because it was only a research project.

Others did not have such good relationships with their case managers:

'I can't tell my case manager what I'd really like.'

Some case managers had failed to achieve what the users wanted - one woman felt she was not getting the help she wanted to get her child back and another wanted to get back to work. Despite what were acknowledged as great efforts, some people still felt lonely in the community.

Some people's initial introduction to case management had been badly handled and the case manager had turned up without warning. Occasionally, case managers turned up with other people and this was not liked by the users. Inevitably, sometimes users did not want to see the case manager.
Overall

'Case management keeps me out of hospital.'

'If it doesn't keep me out of hospital nothing could.'

'Useful but nothing earth-shattering. I get on better with my CPN.'

In summary, the interviews and discussions elicited an overwhelmingly positive response to case management - it was seen as qualitatively different to other services and as a vast improvement. The central relationship between the user and the case manager, as the means of negotiating a better life in the community, was understood and appreciated. Case management did not always work perfectly and could not compensate for service gaps and failures, but it was better than what went before and its loss was feared.
3 Feedback to the Teams

The researchers welcomed the co-operation given them by the case management teams and wished to feed back some of their findings, (especially as people working on the ground often feel anxious about what research will show and are sometimes the last to know the results). Because of time constraints, one site had written feedback only, but direct feedback was given to teams at the other sites. The researchers were impressed at the openness of staff in these discussions and their willingness to discuss the current stage of development of their team. It was dear that the teams were at different stages in the move to user empowerment, but team members were aware of this and were constantly reflecting on what they were doing, and what they could do better. The researchers noted a significant shift in their attitudes to the people receiving case management. In the early days of the project, The Sainsbury Centre User Group had worried about the view case managers had of their clients (which at that stage had not been a 'strengths' approach and had seemed disempowering). The user researchers now felt that, as result of case managers seeing their clients in their own homes - involved in different activities and not just in crisis - they had come to value users as real people, seeing their strengths and beginning to work with them.

The research and the discussions with the teams, highlighted the implications for training and recruitment. The case managers were very clear that their role differed significantly from that of other professionals. Staff had to link both health and social needs and be prepared to do whatever was necessary. Team building was a necessary part of the support structures needed to do this work and ongoing training had dearly helped case managers to develop their attitudes and ways of working.

Some teams had encountered resistance from the other services, who sometimes felt that case managers were checking up on them. Indeed one or two of the users reported noticing some conflict between the different services in the early days of the project, which had made them feel slightly insecure. Interventions by The Sainsbury Centre project management had resolved many of the issues and case management was now a more integrated and accepted part of the service in each district.

In some districts there was a major concern about the future of the project. As always with pilot projects, there had been a lot of advantages in terms of extra training and initially protected resources, but towards the end of the special funding period concern arose about the future funding of the service. This anxiety was felt not only by the case managers but also by the service users, who felt that case management had demonstrated its value and, therefore, no justifiable case could be made for discontinuing the service.
4 Recommendations

For Purchasers and Providers

1. Service standards which value, empower and enable users must be specified.

2. Services which recognise the importance of ongoing, continuous relationships between user and key worker must be developed.

3. An intensive community support team should be available for the most vulnerable people in all localities. The values of client self-determination and building on strengths should be central to all these teams. Adequate support and supervision should be provided.

   Such teams would provide a much better solution for users than Community Supervision Orders. Supervised discharge and 'at risk' registers are seen by most users as an extension of social control rather than concern. We fear that these developments would create a policing relationship between users and their workers, which will prove divisive, and prevent the formation of trusting relationships.

4. Users should be involved in the recruitment of their workers. Wherever possible, users should be able to choose the gender of the person who works with them.

5. Case management should not be seen as a substitute for the availability of other services. It cannot make services available that do not exist. In particular, the opportunities for valued work and leisure do not exist.

6. Users should be trained to work as case managers.

7. Purchasers should give user fora the formal opportunity to monitor and review the effective functioning of case management teams.

8. Case management teams should be as sensitive as possible to the needs of ethnic minority users.

For Researchers

1. Researchers should remember that users prefer to be worked 'with' rather than 'on'.

2. It is vital that users be involved in the early part of a research project, in defining and crystallising research questions, for example through focus groups.

3. User researchers should be used more widely in the evaluation of services. User researchers bring a new and different perspective, which generates new ideas and constructs and enhances the quality of the whole research process.
For Users

1. Do not rush into undertaking a research project commissioned by someone else without thinking through practical and ethical issues, for example, how and in what way will the results be disseminated? Will users have full editorial control? Are the funding arrangements, such as for user salary and travel arrangements, adequate? Can issues of concern be followed up effectively?

2. Develop alliances and arrangements with research organisations that contain all these features.

3. Do not hesitate to ask for additional assistance if that is required.
References


Appendix

User Survey of Case Management Services

Guide to interviews with service users

Notes:

1. Your interview should cover the areas listed but you may use your own style of questions and you may cover the areas in any order you like. You may also wish to follow up any additional areas that emerge during the interview.

2. For some interviews or group discussions you may find the guide most useful for writing up the interview afterwards.

Introduction

What is ‘s (name of worker) job.

The aim of this interview is to feed back your views on the case management service. We are not checking up on your CM. Anything you tell us will be kept confidential and it will not be possible to identify you in any report that we make.

1. Satisfaction with Case Management

What do you like about case management?

What do you dislike about case management?

2. User Input to Care Plan

How did your CM go about finding out what you wanted?

When you meet with your CM, who decides what you talk about?

Can you request a meeting if you want one? and what happens when you do?

Are you satisfied with the contact you have with your CM?

Have you set any goals/aims/targets with your CM? - how were they set?

If you want to do something how does your CM usually react?

If you don't want to do something how does your CM react then?
3. **Access to Services**

Are you receiving the mental health services that you feel you need?  
(may need to give examples of typical services)

Are there some services you would rather not have?

Does your CM check that you are receiving the agreed services?

How is case management different to other services you have received?

4. **Case Management and Advice**

Who would you contact if you felt particularly upset? 
(if user mentions an unpaid carer, ask which professional would they contact?)

Who would you contact if you had a problem with your benefits /pension?

Who would you contact if you wanted to discuss your medication?

Do you feel you can talk to your CM?

5. **Quality of Life**

Do you think that your life has changed since (date)? - use the date case management started, try not to mention case management itself.

What effect do you think case management has had on your life?

Check list: Living situation  
Relationships with family  
Relationships with other people  
Use of leisure time  
Keeping occupied  
Health  
Personal safety (How safe do you feel?)  
Religion  

Have you had the same CM since you started? - tell me what happened if you didn't.

6. **Catch All**

Is there anything else that you would like to tell me?

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