Outcomes in Community Care Practice

NUMBER FOUR

The perspectives of users’ and carers’ organisations

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1. Introduction

The growing interest of policy makers in the topic of outcomes is shown by the recent ministerial foreword to the Community Care Development Programme, launched in 1995, when the Secretaries of State for Health and the Environment signalled that the future development of community care would focus more on outcomes than processes. It was made clear that outcomes were effects on the lives of users and carers, and that these were ultimately far more central to the objectives of community care than changes in the structure or activities of service agencies. The importance of outcomes has also been highlighted by members of users’ organisations (as in Jenny Morris’s *The Power to Change: Commissioning health and social services with disabled people*, published by the King’s Fund Centre in 1995).

The Social Policy Research Unit is working on a programme of research which aims to develop and test ways in which organisations which provide or purchase social care can routinely gather information about the outcomes they are achieving. In pursuing this research, we have taken the view that a range of different groups have a legitimate interest in outcomes, and whether they are achieved. These groups include actual and potential users of services, their carers, professional staff, managers, local and central policy makers and, ultimately, the general public. We intend to carry out local research and development work with users, carers and Social Services Departments (SSDs) in a number of localities, to explore ways of collecting and using outcome information. Since our research is funded by the Government, and the brief derives from the Department of Health, we do not claim to be undertaking user-led research. Nevertheless, our reading of the literature and our existing contacts with users lead us to believe that many users, too, consider it important to focus attention on the effects that services have on people’s lives. An underlying principle of our programme is that the views of users and carers will be of key importance in identifying relevant outcomes and in deciding how they might best be assessed.

As part of the preliminary work designed to lay the foundations for the programme, we have conducted four studies: a literature review; a series of seminars to consider existing knowledge about outcomes and its relevance to the work of social care agencies; interviews with social services managers and planners; and a survey of the views of users’ and carers’ organisations. This report presents the findings of the fourth of these studies.
The aims of this study were to find out from users’ and carers’ organisations:

- how important they believe it is to examine the impact of community care services;
- whether they have carried out any work related to our programme on outcomes;
- what issues concerning the effects of community care services are of particular importance to them and should be included in our programme.

We felt it was important to obtain the views of a number of different organisations. Given that our own programme was planned to focus on services for older people, people with physical impairments, and family carers, we limited the study to organisations which worked primarily with those groups. The organisations we contacted included organisations known nationally or with whom we had previously collaborated. Many of them were not primarily organisations of users of community care services: most had a broader remit to represent the views of older people, disabled people or carers, either in relation to the planning of local services or as broader campaigning bodies. Some provided services, sometimes on contract to local authorities. Some were controlled and staffed by the people they represented; others worked closely with those people and sought to address their concerns. The sample was limited to England. While we were not able to ensure that it was representative, we hoped it would provide a range of different views and experiences.

Given the variety of organisations, each with their particular area of interest and specific focus for their work, we felt that the most appropriate way to obtain their views about community care outcomes would be by means of a brief, open-ended questionnaire, which included the three questions listed above in relation to the aims of the study. Our intention was to attract a wide range of responses that would indicate respondents’ concerns about community care outcomes, as well as issues that need to be examined further. The responses we received indicate that there are many such issues, and that the question of outcomes is indeed an important one.

We sent the questionnaire, together with a description of the research programme, (see Appendices 1-3) to 44 organisations. Contact was made by telephone with organisations which did not reply to the initial letter. Some organisations also asked
for additional copies of the questionnaire to distribute to constituent organisations or individual members.

A total of 40 responses were received (including 32 completed questionnaires, six telephone discussions, one letter and one face-to-face interview). The organisations that responded comprised eight national organisations and 30 regional or local organisations (see Appendix 4). Individual responses were received from two members of a local organisation. Of the organisations that were contacted by telephone but did not subsequently make a more detailed response, many indicated that the examination of outcomes was important (none stated it was unimportant); they referred, however, to the pressure of the work that had prevented them from replying. Organisations had also been asked to give details of any reports they might have produced about relevant work they had carried out, and several enclosed or referred to such reports.

Although the questionnaire referred to both ‘users and carers’, some organisations were primarily concerned with services for one group or the other. In many cases, however, comments were applicable to both groups; where this is the case, the phrase ‘users and carers’ will be used in our report. We recognise that users’ and carers’ interests may sometimes be different. We are also aware of the literature about some disabled people’s objections to the term ‘carer’, with the connotations of dependency that this may evoke - as was indeed pointed out to us by one respondent. Given that our study involved older people’s and carers’ organisations, in which these terms are commonly used, and in order to avoid confusion, we have nonetheless decided to retain their use here.

The following three sections of this report will present the comments made by respondents in response to the three questions indicated above. Although we have organised those comments into sections that appear to us to reflect particular issues, the sections aim to reflect those comments, and not our own views: we shall make some concluding observations of our own in the final section of the report. Where we spoke to people on the telephone or face-to-face, we made notes of the issues they referred to: we hope we have recorded those issues faithfully. A draft version of this report was circulated to all respondents and their subsequent comments were taken into account in the revised text.
All the organisations which returned completed questionnaires believed it was important to examine outcomes. One felt it was vital to examine the effectiveness (and cost-effectiveness) of services. Another said it was ‘self-evidently important’ to look at the impact of community care services, adding that ‘the services are provided to meet the needs of users and carers and thus some estimate of outcomes in the sense of people’s estimate of the value of such services is vitally necessary’ (Camden Age Concern). The Centre for Policy on Ageing noted that:

The purpose of the community care legislation (or at least one purpose) was to provide a more appropriate and acceptable service to users. Unless users/carers are asked what their experience has been, the success or failure of the new service will never be known.

Derbyshire Centre for Integrated Living (CIL) suggested, in addition, that disabled people might be sceptical of any definitions of outcomes that did not take full account of their own objectives for services. For instance, an outcome that might satisfy managers - such as achieving the relocation of people from hospital to residential care - might be a wholly negative personal outcome for the individuals.

Respondents noted five principal reasons why outcomes should be monitored:

- to shift the focus of attention to users’ and carers’ needs and away from organisational issues;
- to show that the community care arrangements are not in fact achieving desired objectives;
- to provide credible evidence about services;
- as a form of accountability and means of checking whether agencies meet users’ needs;
- to inform the continuing development of services.

These five points will be discussed below.
Shifting the focus to users’ and carers’ needs

For many respondents, a concern with the impacts of services provided an opportunity to focus attention on users’ and carers’ needs rather than organisational issues. Financial constraints meant that services were often resource-led, and the community care debate was frequently more concerned with political objectives and issues of cost rather than with users’ needs. In addition, some service providers were said to feel they know what is best for users: such a view, too, needed to be challenged. Existing consultation processes, for their part, were still inadequate: housebound older people, for example, were not necessarily included in consultation procedures.

Several respondents believed that the monitoring of service outcomes would help to focus attention on the needs and quality of life of users and carers, and show how well their needs were being met. Some referred to the need to ask users about their experiences of services, and to monitor the quality and flexibility of those services. Others stressed that users and carers should be able to define what services they required in order to meet their needs. One respondent referred specifically to the need for users and carers to have a means of influencing the types of services available: they should be seen as partners with professional staff. Again, this would have an impact on the outcomes that were achieved. Another noted, more specifically, that partnership would enable service planners and providers to ‘get it right’ by being sensitive to individual needs and ensuring that users were able to exercise choice and control over the services they received. At a collective level, consultation with users and carers needed to be more than merely ‘tokenistic’. One respondent, however, felt that achieving such change would require a culture change within SSDs.

Another stated that the monitoring of outcomes is not of real concern to individual users or carers, who are already aware of the effects that services are having: but it is very important for professionals, planners and politicians to have this information. It is vital, then, to ask users and carers about their experiences: without such information, it will not be possible to establish either the success or failure of community care services. Monitoring will also help establish the extent to which services are user-led. In addition, users and carers need to have an input into the monitoring process, and help identify how this might be carried out most effectively.

The failure of community care to achieve desired objectives

Many respondents felt that looking at outcomes was important because it would underline what they believed was the failure of the new community arrangements to meet users’ and carers’ needs. One felt that ‘nothing could be more untrue’ than
to assume that community care was working in the way that had been intended. Budget cuts, tightened eligibility criteria, and ceilings on care packages meant that previously available services were being reduced or withdrawn. For several older people’s organisations, the withdrawal of housework was seen as causing difficulties. One suggested that:

The fact that the user is able (very slowly) to get up in a morning and get themselves to bed at night doesn’t mean they don’t get depressed looking at housework they are unable to do. To have someone there for one or two hours once a week (or more often fortnightly) was often quite a lift to their spirits. (Wolverhampton Pensioners’ Consortium)

Elsewhere, an SSD had ceased funding both an equipment service that had been based at a Centre for Integrated Living and participation in a taxicard scheme - even though, according to the respondent, these services provided flexibility and a more immediate and responsive service to meet disabled people’s needs: services in that area were being ‘cut to the bone’. A respondent in a different area referred to ‘survival only’ services being provided. In many places, services for both users and carers were said to be either unavailable or were being rationed: one stated that community care was ‘failing to provide all the services to all the people who need them’ (Association of Greater London Older Women, emphasis in original). Several respondents expressed concern about the lack of preventive services. One felt that, although the rhetoric referred to user-centred services, cost constraints and organisational pressures had prevented improvements from taking place.

A number of people were vehement in their criticisms of SSD policies and practice, and of the impact of these on users. A disabled people’s organisation criticised one SSD for protecting its own home care service, which many disabled people did not want. In another area, most care managers reportedly did not understand the social model of disability or know how to carry out needs-led assessments. Such factors prevented users from exercising choice and were likely to ‘restrict and institutionalise’ them.

In such circumstances, it is perhaps not surprising that one respondent was ‘so angry about what has happened to community care’ that he felt that a focus on outcomes appeared to deny the reality of the problems that existed. On the other hand, another respondent made the point that it was very important to examine outcomes, precisely because community care was not achieving what it had promised. Several people referred to the need to examine the impact of current policies on people who did not receive sufficient services or who ‘fell through the net’, for instance by not meeting new eligibility criteria. These issues of distribution
and targeting of services also occurred in answers to our questions about further areas for examination, and are dealt with at greater length in that section.

Although many respondents referred to problems in the way the community care arrangements were working, one person did mention some positive changes that had occurred: an increase in day care for older people, more personal care, and improvements in short-term breaks for older people. In such circumstances, too, it was seen as important to monitor services to ensure they were of high quality and met users’ and carers’ needs appropriately.

The examination of outcomes would also provide a means of highlighting a number of other policy issues relating to community care. These included:

- variations around the country in the way that agencies carried out their responsibilities;
- the impacts of services on people from minority ethnic communities: the Black Disabled People’s Group stated that no note had been taken of different cultural, religious or linguistic needs in the provision of services for disabled people, and those needs therefore remained unmet;
- the need to acknowledge the contributions made by carers, as well as the support they themselves needed.

**Credible evidence about services**

One respondent stated that local authority councillors lacked a real understanding of how to assess quality, and objective information was needed about the effects that services had on users and carers. Surveys, according to another, would be of more value than some current forms of consultation. However, service commissioners, providers, users and carers all had to be confident that the methods used to obtain this information were appropriate and reliable. One respondent stressed that independent research should be conducted from a disability equality perspective. Anonymity might also be necessary, so that users did not feel reluctant to voice criticisms, especially about service providers with whom they were in daily contact. Indeed, one respondent thought there might be a role for voluntary organisations in collecting evidence about services: older people, in particular, were sometimes more willing to tell voluntary organisations about failings in, for example, contracted-out home care services.

Another pointed out that many users were unaware there might be different, or better, ways of meeting needs: information about the impacts of services would help to highlight the possibilities that exist. Such information might also illustrate the
problems for users and carers arising from SSDs’ narrow interpretations of their responsibilities concerning, say, the provision of assistance with holidays or help with cleaning.

A member of a disabled people’s organisation felt that information on outcomes would allow comparisons to be made between the experiences of people receiving community care services and those who controlled their own personal assistance arrangements (with, in the latter case, funding from the SSD and the Independent Living Fund). Evidence about outcomes offered a way of comparing these two types of arrangement. Another person suggested that any examination of outcomes for disabled people should be undertaken from a disability equality perspective.

**Accountability**

Evidence about the impacts of services provided a means of monitoring whether services matched both the expectations of users and carers, and also the objectives set out in SSDs’ Community Care Plans: it would thus provide a form of accountability and would indicate the extent to which community care was indeed working for the benefit of its users. One respondent felt this was increasingly important as more services for vulnerable people were being contracted out: the information would contribute to the regulation of the standards of care being provided. Another suggested that a comparison of authorities would indicate whether some were meeting their responsibilities to users and carers more effectively than others.

**To inform service development**

Some respondents stated that the monitoring and evaluation of service impacts was central to the planning and development of needs-led services. Such monitoring would indicate whether services were meeting users’ and carers’ needs, whether they were of a sufficiently high quality, and what changes needed to be made. One person pointed out that if services were failing to meet needs appropriately, this did not only cause distress: it also represented a waste of money.

The person who suggested a comparison between SSD services and services that were under users’ control called for community care policies to be reformed, so as to give users more freedom and independence in the way they lived their lives. Others felt that the forthcoming introduction of direct payments could help to achieve this by showing service agencies what services were needed: one stated that users’ choice of provider would indicate the outcomes that people wanted.
4. Work already carried out

The second set of responses reported here concerns activities in which organisations were involved, relating to our own programme of work on the outcomes of community care. Those activities were in the areas of:

- facilitating user and carer empowerment;
- needs assessment and service evaluation;
- influence in service planning and development.

A list of reports enclosed or referred to by respondents is included in Appendix 5.

Facilitating user and carer empowerment

Several of the organisations which responded were established specifically to facilitate user and carer empowerment: one of their primary roles was thus to enable users and carers to identify the services they needed in order that they could then exert influence over local planning processes. The Clients Council for Older People in Sunderland, for example, was established in order to involve service users and carers more in the planning and monitoring of services, and to ensure that services were responsive to people’s needs. It sought to do this by supporting local groups of older people to identify issues of concern and feed these in to service planners and providers. The same was the case with the SCIPSHA (Senior Citizens Involved in Public Services, Health and Advocacy) Programme set up by the Beth Johnson Foundation in Staffordshire, and the SCOPE (Strategy for the Care of Older People in Eastern Wiltshire) project, which was set up by the Wiltshire Community Foundation (WCF) and jointly managed by WCF and Age Concern Wiltshire. The latter project had involved older people in a number of localities identifying services which would ‘maximise their potential to lead an independent life in the community’. In addition to leading to local service developments, the project had produced a strategy report which had been adopted by the SSD and Health Authority (HA) as the basis for their joint strategy for older people. Age Concern Liverpool had established a number of consumer councils as a form for debate, the Association of Greater London Older Women had arranged meetings for older women users and carers to find out their views about community care services, and Help and Care, working in Dorset, provided support for a forum of older people whose views were then passed on to the SSD and HA.

The Greater London Forum for the Elderly had initiated and run a two-year project entitled ‘The Older Voice in Community Care’. This provided training and support to
enable 14 older people to take part in community care planning and implementation consultation in seven London Boroughs. In Wakefield, the Age Concern Service Users' Action Forum was about to undertake a 'Talk Back' project with frail older people. Funded through the Department of Health's Community Care Development Programme, volunteers would be recruited to visit housebound people over 75 and, over a period of time, record people's thoughts and feelings about the community care services they received, and how they would like those services to be organised and delivered. The project, which also involved the SSD, HA, users' groups and Community Health Council, would assist service providers to tailor their services to meet better the needs of housebound older people.

One of the roles of disabled people’s organisations, too, was to act as a forum for disabled people in seeking improved services. Several of these organisations had been established by disabled people in order to campaign for more appropriate services that would enable disabled people to lead independent lives and exercise control over the services they received. Many organisations were under the collective control of disabled people and had the brief of reflecting the views of their members.

**Needs assessment and service evaluation**

Some organisations had carried out specific studies to canvas the views of their memberships, or of service users more widely, on particular issues. For example, the Centre for Policy on Ageing was examining the service needs of older people with learning difficulties; it had also undertaken a study of the health service needs of older people from minority ethnic communities.

**SSD services**

A number of surveys had focused on the impact of specific SSD services. Age Concern London had carried out an investigation into home support for disabled older people. Their interviewees referred to the impact on them of: insensitive or haphazard assessment practices resulting in appropriate service provision; a lack of or reductions in services; inflexibility or insensitivity in the services they did receive; and the neglect of needs for services that disabled people themselves had identified. A second study examined the support provided for older people after discharge from hospital. It identified the negative impacts of overstretched hospital staff, a lack of information about benefits and medication, poor liaison with GPs, inappropriate transport home, the lack of home assessment (or sometimes of any assessment), the provision of inappropriate equipment, and lack of advice on adaptations. On the other hand, the positive features of special hospital aftercare schemes included smooth transition and liaison, their preventive role, responding
to previously unidentified needs, information about rights to benefits and services, and the provision of reassurance.

A study mentioned by the Centre for Policy on Ageing also examined older people’s satisfaction with discharge procedures in one health authority area. Wandsworth Pensioners’ Forum had obtained older people’s views on home care, and Age Concern Wiltshire had examined a number of day centres and luncheon clubs that were funded by the SSD. Brent Pensioners’ Forum (BPF) had published a report on the impacts of the withdrawal, reduction or failure to provide home care services, including the risk of ill-health and disease, mental distress, and a lack of safeguards against crisis; the report stressed the importance of preventive services. While essentially a campaigning document, the report quoted from a survey of users and carers that had been commissioned by the SSD and which stated that ‘users do not feel that they have control over the resources; they are told what the services will be for and cannot convert the hours to their own preferred use. This is seen as disempowering’. The BPF report noted that the rhetoric of user involvement was thus contrasted with reality.

Among disabled people’s organisations, the West of England Centre for Integrated Living had carried out a series of consultation meetings with disabled people on housing and community care, and had subsequently published a report. This CIL was currently involved in a Care Management Advocacy Project which aimed to identify gaps in provision and their impact on disabled people. Elsewhere, the British Deaf Association had reviewed services for Deaf and hearing impaired people in specific local authority areas. A study by RADAR, entitled ‘Disabled People Have Rights’, examined the problems that disabled people faced in obtaining services under section 2 of the Chronically Sick and Disabled Persons Act 1970. Those problems included reductions in or the withdrawal of services, the failure to provide domestic assistance, the imposition of or increases in charges, lack of cover when home carers were unavailable, delay in the provision of occupational therapy assessments or subsequent services, unreasonable financial assessments for adaptations, lack of flexibility in meeting needs, and failure to meet identified needs.

Two surveys had also been undertaken by the Carers’ National Association to identify carers’ views about the effectiveness of community care. The report from the second of these set out a policy agenda for improvements in services for carers.

Some organisations were particularly concerned about the impacts of changes in provision or policy. This was the case with the BPF report; in the case of Wandsworth Pensioners’ Forum, the instigating factor was the privatisation of some local services. The Clients Council for Older People in Sunderland had asked service users and carers to monitor what changes - and any improvements - in the
services they received. And the Crossroads Association’s Caring for Carers project was beginning a study of the impact of the Carers Act.

Two organisations had developed quality standards for monitoring services. Help and Care, working in Dorset, had designed a ‘Quality Perception Service’ which was complementary to the principles of Total Quality Management. This involved users in informal discussions about the services being delivered, and information was then fed back anonymously to service managers. The main problem, however, was the difficulty in obtaining funding for such work. The second initiative, by the Princess Royal Trust for Carers, had used the British Quality Foundation Model and ISO 9000 to develop a Quality Manual. This was designed to assist small projects to gather feedback from carers about their experiences of services and to monitor outcomes; the methods to be used could include surveys or focus groups.

**Services provided by organisations of and for older people, disabled people and carers**

Other organisations had evaluated the services that they themselves provided. Camden Age Concern had instituted an ongoing monitoring system to find out whether users of its information and counselling service (designed ‘to promote independence and improvement in the quality of life of older people’) had obtained the advice or information they needed, as well as their satisfaction with the premises and organisational arrangements. Age Concern Liverpool also monitored the services it provided, and Scarborough and Ryedale Carers Resource had sent a monitoring questionnaire to carers about the services it offered. Greenwich Association of Disabled People had published reports on personal assistance schemes and training in independent living, while the Sutton Centre for Independent Living and Learning carried out consultations with users to identify the impact of its services and obtain ideas for additional innovative services.

Some organisations did not specifically refer to service evaluation, but mentioned services that they provided. The services provided by organisations of disabled people (such as Derbyshire and Southampton CILs and the Greenwich Association of Disabled People) were often designed to meet people’s needs more effectively than SSD services. Some organisations sought to meet needs that were not being met by the statutory sector at all. Help the Aged and the Disability Rights and Resource Centre (York), for example, ran telephone advice lines; Mansfield Pensioners Action Association assisted people to claim social security benefits; and the Wolverhampton Pensioners’ Consortium had obtained finance for home security items for older people.
Projects planned
Some organisations were planning to undertake further monitoring. Camden Age Concern was proposing to interview random samples of users of its services, with assistance from sixth-formers. Age Concern Wiltshire was holding discussions with the SSD about a survey of users of older people’s clubs.

A major project was about to be undertaken by Southampton CIL. It had received funding from the Department of Health’s Community Care Development Programme for a series of consumer audits of services for disabled people. An agency would be commissioned both to carry out specific audits and to train users to undertake audits themselves. Guidance would be produced at the end of the two-year project on appropriate audit tools. The focus of this work would be on outcomes, such as choice, control, people’s views of independence, and achieving a high quality life. The project involved the SSD and HA and would provide information to inform their commissioning processes.

Influence in service planning and development

By taking part in formal service planning alongside statutory agencies, many respondents felt they could help achieve better outcomes for users and carers. A number of local organisations (and constituent members of wider groupings such as the Greater London Forum for the Elderly) were involved in joint planning groups, consultation procedures and inspection teams. Some mentioned their involvement in discussions on specific issues, such as quality standards. Wiltshire Users Network referred to a wide-ranging approach to influencing service planning and provision:

By riddling the Social Services Department with as many users’ perspectives as possible at all levels, we have sought to change the culture of the organisation to one where users’ views are the starting point for definitions of quality and service outcomes. There is increasing evidence that in local teams a bottom-up approach is the way they are approaching developing quality standards in care management and specific services such as OT services.

The British Deaf Association had undertaken development work in a number of SSDs in order to involve users in service planning. Similarly, the Camden Forum of Elderly People, in conjunction with the Camden Healthy Cities Project, was examining ways of enabling housebound older people and their carers to have a say in service planning and delivery; a recent newsletter suggested that training for professional staff should be carried out in conjunction with housebound older people and their carers.
Some organisations mentioned that they had been involved in developing user influence in health service planning. The Greenwich Association of Disabled People had commissioned a survey on behalf of a health authority, to obtain the views of disabled people about the wheelchair service and other health services. It sought to develop user-led specifications for services and to change services in ways that empower disabled people and are easier for them to use.

Many of the national organisations had a remit to represent users’ or carers’ views and influence policy at a national level. Since such tasks did not involve the examination of outcomes for individual service users, not all organisations mentioned their roles at this level. Nevertheless, involvement in a research project on the roles of social workers, carried out by the National Institute of Social Work, or drawing up guidelines on community care for the British Medical Association (both mentioned by the National Pensioners Convention), undoubtedly serve to extend users’ and carers’ influence in a way that could have an important effect on outcomes for individuals.
5. Issues for further examination

Respondents identified a variety of issues that were of concern to them and that should be taken into account in further research and development into the outcomes of community care. These issues relate to:

- underlying principles;
- factors that affect outcomes;
- services to be monitored;
- desirable services;
- quality issues;
- organisational culture;
- important outcomes.

**Underlying principles**

*Obtaining users’ and carers’ views*

Respondents outlined some principles that should underpin any research or development on outcomes. Some stressed the fundamental importance of obtaining users’ and carers’ views when examining outcomes. One stated that professionals do not necessarily understand what users and carers need:

There is a need to ask users and non-users about their wants. Professionals presume to know the answers to questions before the questions have been asked. There is a difference between suppliers’ views of people’s needs and people’s own wants. (Camden Forum of Elderly People)

One person felt that, because of the low expectations of many users, considerable interviewing skills would be required in order to ascertain their real needs. Another noted that not all users were familiar with the changes that had taken place in policy and practice. Support would be needed to help them become involved in work to examine the impacts of recent developments.
**The distribution of services**

Several respondents stressed the need to examine outcomes for non-users as well as users. They felt there was a danger that the available money would increasingly be focused on those who receive services, to the exclusion of those with lower levels of need, who do not. This was a particular concern in the light of recent cutbacks in services. As a result, some users no longer expected to receive assistance from SSDs. For others, charging policies meant that services were often dependent on the ability to pay; people were thus ‘rationed out’ from services, and ‘a fair and proper distribution of services’ was made impossible. A record of unmet needs was required in order to press for more resources. But there was also a need to obtain the views of people about the impact of needs not being met - despite the acknowledged difficulty of identifying people who are not receiving services.

Other ‘non-users’ included informal carers who do not identify themselves as such and who do not receive services which could assist them. One respondent highlighted the need for services to be accessible to and appropriate for people from minority ethnic communities.

**Factors that affect outcomes**

A number of people identified factors which, they believed, affected outcomes. One such factor was the way assessments were carried out. Some respondents felt there was a lack of consistency in the way assessments were undertaken, even within local areas, and assessments were not always needs-led. One person argued that needs should be identified whether or not resources were available to meet them: the creation of a database on unmet needs was necessary, as ‘without this, resources will not change’ (Age Concern Service Users’ Action Forum, Wakefield District).

Many respondents referred to the shortage of resources to meet needs. Although this was particularly apparent in London, others also mentioned it. The Oxfordshire Pensioners’ Action Group, for instance, stated that we are worried about the effects of LACK of services caused by budget cuts’ (emphasis in original). Charging policies, too, meant that some people were:

forced to accept a level of service which matches not their needs but their ability to pay - or even dropped out of the system.
(Greater London Forum for the Elderly)
Another respondent referred specifically to the:

    effect of relative poverty, which has led to those needing care
foregoing services, e.g. some home care and day centre attendance,
in order to avoid paying for them.
(Islington Pensioners Forum)

While several organisations of disabled people also felt that charging policies were
having a harmful effect on users, one pointed out that ‘ageist double standards’
meant there were upper limits on funding for older people which were not imposed
on younger people.

The lack of effective co-ordination of services was also highlighted: more effective
communication was needed between hospitals, community health, GPs, social
services and housing agencies. However, this meant that issues around ‘the
demarcation between health and social services’ needed to be resolved (Milton
Keynes CIL). Within the voluntary sector, too, there was a need for organisations to
communicate more effectively in order to avoid duplication. Not least, service
co-ordination needed to involve people’s families and partners.

**Services to be monitored**

Some respondents stated that existing monitoring arrangements did not adequately
check the impact that services were having on users. The inspection of residential
homes, for example, was said to be concerned just with buildings, with no attempt
to examine the nature of the actual care being provided. One respondent pointed out
that ‘people in care need a voice’. In the case of domiciliary services, contractual
control did not usually involve obtaining users’ own views about whether the service
was satisfactory.

The forthcoming introduction of direct payments for disabled people was welcomed,
and monitoring would indicate the extent to which users would be empowered to
choose service providers and obtain the outcomes they wanted. At the same time,
it would help establish whether users received the support they needed in managing
the arrangements. It would also be important to take note of the exclusions in the
scheme and consider outcomes for, say, people over 65.

A further area to be examined concerned outcomes for carers as a result of the
implementation of the Carers Act.
Desirable services

A number of respondents identified particular services that should be provided in order to achieve good outcomes. Some referred to preventive services for people who were currently assessed as having ‘lower’ levels of need. Others argued for more sheltered accommodation, recovery and convalescence facilities after discharge from hospital, or services to keep in contact with older isolated and disabled people. One respondent called for ‘listening services’ which would ‘benefit organisations as well as giving value to the experiences, views and needs of individuals’ (Age Concern London). Some respondents highlighted the need for people to have information about services and alternative service providers. Advocacy services were also needed: there was currently a lack of understanding of, and support for, such services. The British Deaf Association noted that the needs of Deaf and hearing impaired users included access to ‘mainstream’ as well as specialist services. Both carers’ and older people’s organisations referred to the need for support for carers. Some organisations of disabled people called for the provision of ‘enabling services’ such as personal assistance schemes.

One respondent also suggested it would be useful to assess the value of preventive services such as day centres, library services, visiting schemes and community health initiatives. Such services were believed to reduce the need for domiciliary care.

Quality issues

The quality of services itself has an impact on the outcomes people experience. Two respondents pointed to the importance of sensitivity in the assessment process. One noted that, for older people, assessments occur at a particularly sensitive and difficult time in people’s lives, when they have come to realise ‘they can no longer live an independent life without professional help’. It seems, however, that some SSD staff fail to appreciate that ‘it is a human being who is asking them to provide some answers’ (Wolverhampton Pensioners’ Consortium). The other respondent, too, noted that the way the needs and services are assessed can be ‘a worrying and upsetting process for many users’ (Association of Greater London Older Women). Greater sensitivity and understanding are thus needed about the effect of the assessment process on people who ask SSDs for assistance.

Carers’ needs also need to be taken into account in the assessment process. Although this applies in all instances, one respondent specifically mentioned the
need to consider the carer’s position when an older person is being discharged from hospital, and when a carer is unable to meet all the person’s needs.

A further aspect of quality concerns the support that people may need in order to make decisions about their lives. A respondent mentioned, for example, that this could include support for the communication needs of Deaf people or people with learning difficulties, who are otherwise excluded from decisions.

Once a service is provided, continuity is important. The point was made that frequent changes in home care staff, for instance, can be frustrating and can cause older people to feel confused.

**Organisational culture**

One respondent suggested that the culture of professional organisations must change so that staff focus on needs, not services: staff must learn how to consult with and listen to users in a meaningful way. There was also a reported need for the barriers between services and between professions to be broken down: the focus should be on meeting users’ needs in the most appropriate way. One person stressed that professionals must also understand the social model of disability, in order to address the barriers that users encounter and enable them to take control over their own lives. Indeed, another respondent stated that disabled people already face oppression: yet since the introduction of new SSD contracting arrangements, there seemed to be an increase in paternalism on the part of SSD staff, and less awareness of disability equality issues. Users and users’ organisations, according to another, should ‘participate in regular ongoing training for all grades of staff involved in community care’ (Arthritis Care, Wiltshire and Gloucestershine).

One respondent felt that, if outcomes were to be examined as a matter of routine, SSDs would need to develop the skills to do this: such expertise, he felt, was currently lacking. Another stated that SSDs have not been proactive about seeking feedback: it was, however, important that they should find ways of obtaining such feedback, both about problems that users and carers still encounter and about the positive aspects of services. SSDs thus needed to become ‘learning organisations’.

**Important outcomes**

Respondents were not asked to specify what outcomes they wanted from services. Some did, however, indicate aspects they considered important.
One person described how SSD services had focused solely on ensuring she ‘stayed clean, hygienic, and did not starve’. In addition:

I had to fit in with their hours, go to bed when they wanted, hang around until they arrived, some of the home helps were very lazy. I could only have the help they thought was essential like bathing, dressing, shopping, cooking etc. I could not go to the shops or the cinema. I was always thought of as awkward because I challenged different ways I was treated, or not treated, as if I was a nuisance. By keeping help to the absolute minimum was the only way I could keep my individuality, my sense of freedom, but it meant that some of my most basic needs remained unfulfilled.

(Member of Greenwich Association of Disabled People)

She subsequently obtained funding to arrange her own personal assistance, as a result of which:

My whole life has changed and my whole attitude to life. I now feel like a respectable member of society. I can now fulfil my own aims and the potential for improvement is enormous.

Another member of the Greenwich Association of Disabled People pointed out, in relation to independent living, that ‘we are totally in charge of everything that we do in our day to day living’ (emphasis in original). The question of control was thus paramount. Other respondents identified desirable outcomes which, in their opinion, were not being achieved because of the impact of current policies. Some, for instance, felt that the emphasis on choice, sensitivity and flexibility in current community care policies was little more than rhetoric, and that it masked the real deficiencies in services and lack of choice due to financial constraints. Others commented on the prioritisation of need and the provision of services only to people in ‘life and death situations’. This meant that the objectives of community care, in terms of an improved quality of life, were not being achieved for many people. In such circumstances, they suggested, additional funds needed to be found in order to achieve those aims.

Many of the comments made by respondents related to negative outcomes: to the bad effects of services. It does seem easier to identify problems than to specify the positive things that services are supposed to achieve. For instance, some people wondered what the quality of life was like for people who only received a ‘subsistence level of care’: one person suggested that people’s physical health was suffering as a result of service inadequacies and the stress these caused. A number
of older people’s organisations stated that many older people were concerned about the lack of domestic help: they saw such help as extremely important. One respondent felt that, if people felt neglected, disempowered or ignored, this could cause mental stress; and emotional needs were not always taken into account when needs were being assessed. Safety and security, too, were important issues for older people: it was important to reduce the fear that many older people felt in their homes and neighbourhoods. For some older people, the comfortable surroundings of a residential home and the choice of company when they wanted it might be preferable to feeling isolated in their own homes.

These comments about negative outcomes provide a way of identifying the outcomes that services should achieve. Thus, some desirable outcomes, based on the above points, might include: good physical health, feeling at ease, and feeling secure.

Finally, the style or process of service delivery was seen as highly important. One suggestion was that a number of indicators could be developed to demonstrate whether services empowered users: those indicators might include factors such as services being non-patronising, whether users could exercise control over them, and whether confidentiality was respected.
6. Conclusions

This study was designed to find out whether users’ and carers’ organisations believed it was important to examine outcomes of community care, and to identify specific issues that would inform our own programme of research and development. Understandably, many of the comments we received related to the impacts of current policies, and the services required to achieve appropriate outcomes, rather than to specific ways in which SSDs might obtain routine feedback about the impacts of services or the precise aspects they might need to examine. Nevertheless, the questions we raised appear to have struck chords with many of the organisations we approached, and we are grateful to all those who took the time and trouble to respond to our questionnaires and telephone calls. In this final section, we will draw out some of the main points that organisations made and consider their implications.

A number of organisations were already involved in evaluating services, whether provided through local authorities or by the organisations themselves. Some were involved in developing quality standards. Although none of the written feedback referred specifically to monitoring outcomes as part of their current work, the idea of outcomes was certainly implicit in many of the comments. Some of our telephone respondents pointed out that outcomes have always been a key part of their approach to service evaluation, even though it is only recently that the word ‘outcome’ has become more prominent. The comments we received did illustrate that respondents were concerned about negative outcomes such as mental distress or increased risk; others pointed to positive outcomes such as the greater independence that some services could bring. Respondents also noted that the way in which services were delivered had an important impact on users, whether in relation to a lack of control over services, delays in assessment or a lack of sensitivity at difficult times in people’s lives. It is therefore important, when examining outcomes, to take account of the effects that the process of service delivery has on users.

Organisations stressed, almost unanimously, that it was variously ‘vital’, ‘essential’ or ‘very important’ to examine outcomes. Many felt this was a key way to obtain evidence about the effectiveness of community care policies. In particular, they expressed concern about the possible consequences of targeting services on people with more complex and urgent needs: such targeting meant that people with apparently less urgent needs were not deemed eligible for services, or services were withdrawn from some people who had previously received them. Evidence
about outcomes would, they felt, provide the broader evidence that was needed in order to demonstrate what was currently happening, and what needed to be changed.

One respondent pointed out that individual users do not need to find out about the outcomes that services are having for them: they know this already. Such information is needed, however, by the managers and planners who are responsible for providing or developing new services, by outside bodies such as users’ and carers’ organisations which wish to monitor the effectiveness of provision, and by future users who may wish to choose between different types of service provision and will need to know which are the most effective.

Respondents made few comments about the precise ways in which information about outcomes should be obtained. Some referred to quality assurance methods such as focus groups; others mentioned surveys. Different methods are likely to be suitable for different purposes. Where the intention is to examine service impacts in detail, an open-ended approach may be the most suitable. If, on the other hand, the aim is to examine broader services or policies, it will be necessary to generalise from a large number of users. At present, it is unclear exactly what sorts of questions need to be asked in order to obtain such information, or how much detail it would be necessary or appropriate to ask for. One respondent was certainly sceptical of the ability of both local authorities and the voluntary sector to obtain reliable information. Others pointed out that any approach to examining outcomes must have the confidence of all the parties involved, including users and carers. Our own intention is to develop appropriate and reliable methods for examining individual outcomes in the course of regular practice. The above comments, however, indicate some of the complex issues to be addressed, and it is not clear how easy it will be to achieve a consensus between the relevant parties or to address issues in a way that all consider appropriate.

We attempted, in the questionnaire, covering letter and accompanying leaflet, to clarify the purpose of both our programme and this consultation (see Appendices 1-3). Nevertheless, we recognise, in retrospect, that we may not have managed to make an adequate distinction between the outcomes of community care policies and more specific ways of examining outcomes for individuals. While our brief is to focus on the latter, the understandable concern of many organisations is with the inadequacies of existing services and with alternative types of services that people believe would better meet their needs.

That concern needs to be taken into account in any future work on outcomes. In the first place, we need to be clearer about the way we describe our own objectives. Secondly, this study suggests that individual users’ views of their own outcomes are
likely to be tempered by their perceptions of outcomes for people whose needs are not being adequately met. Thirdly, it is important to identify the terms and concepts that users and carers find most meaningful when talking about outcomes. Identifying inadequacies and negative outcomes would appear to be easier than specifying positive outcomes. Exploratory work could, therefore, usefully examine the possibility of using negative terms to develop definitions of desirable outcomes.

Importantly, this study has highlighted the need to take account of the views of people not using community care services. Some members of disabled people's organisations used services arranged either independently or through those organisations: they provided a perspective on the objectives of personal assistance services which might well not have been possible if we had consulted solely with users of local authority services. When looking at community care services, the views of people using alternative services can thus shed an important light on the outcomes which community care should also seek to achieve. In addition, the concern of many organisations about reductions in or the non-availability of services raises important issues in respect of people whose services have been reduced, or who do not satisfy current eligibility criteria. We do not currently know at what point it is most effective to provide services: it is, therefore, important to identify the effects on people of not receiving services.

Although some of the concerns expressed by users' and carers' organisations extend beyond our own immediate programme, the issues they have highlighted need to be taken into account when examining the impact of broader community care policies. At the same time, many users' and carers' organisations are developing an expertise in service evaluation which can make a vital contribution to the examination of outcomes for individuals. If the methods to be used in relation to outcomes are to reflect the experiences of users and carers, it is essential that they, and their organisations, should be fully involved in the process of developing them.
Dear

We are carrying out a programme of work for the Department of Health on the effects of social support and community care services on users and carers, and on how to examine those effects in a routine way. The attached description of our programme sets out the questions we have identified so far.

As part of the work, we wish to obtain the views of users’ and carers’ organisations about the issues they consider important when looking at ‘outcomes’ and we are contacting a number of national umbrella organisations and local organisations of service users and carers. I enclose a brief form with a few broad questions about aspects you may consider relevant. If you (or a colleague) would like to complete it and return it to us in the reply-paid envelope provided, we should be very interested in your comments. The form itself is short, but we would also be interested in any additional comments or papers you might wish to enclose. We hope you will be able to respond on behalf of your organisation, but we would be happy to provide more copies of the description and form if you would prefer to distribute them to your members.

Our intention is to draw together the results in a brief report, which we will submit to the Department of Health together with recommendations for future research and development that might usefully be carried out. We will be happy to send you a copy of the report once it becomes available.

We would be grateful if you could return the form by the end of May. However, if this deadline is unrealistic, please could you let us know when you might be able to return it.

Do feel free to contact me if there are any aspects of this letter you would like to discuss further.

Yours sincerely
EXAMINING THE OUTCOMES OF COMMUNITY CARE

Name of organisation:

1. Has your organisation carried out any work relevant to our programme (see attached description)? If so, please indicate what this has been.

2. How important do you think it is to look at the impact of community care services for users and carers? (Please explain why.)

(please turn over)
3. Are there any issues concerning the effects of services that are of particular importance to you and that we should include in our programme?

4. If you feel it would be helpful to discuss your experiences and views further by phone, and are willing to be contacted, please give a name and contact number below.

Thank you for completing this form
Please return it in the reply-paid envelope provided.
EXAMINING THE OUTCOMES OF COMMUNITY CARE FOR USERS AND CARERS

♦ Are community care services providing what people really need?

♦ What effects do they have on the lives of people who use services and on family or friends who assist them?

♦ How can we tell whether services have made any difference to the things people are able to do and the way they feel?

♦ Are there easy, straightforward ways in which social services departments, users and carers can regularly check on the impact of community care services?

Such questions are central to a new programme of research and development on the 'outcomes' of community care for users and for carers. The programme is funded by the Department of Health and being carried out by the Social Policy Research Unit.

The new community care arrangements stress the importance of starting with what users and carers need and arranging services to meet those needs. But just providing services is not enough. We need to know whether they do in fact meet people’s needs. Most importantly, we need a way of routinely monitoring the impact of what is provided, so that any mismatch between what people need and what is on offer can be put right.
Service users, carers, practitioners, service planners, managers and politicians all have a stake in assessing the effectiveness of community care services. But in this, as in other aspects of community care planning and service development, users and carers have the central role.

**What users and carers want from services**

First we need to be clear about what users and carers want from services. This new emphasis on outcomes gives users, carers, and their organisations the chance to set out what they think services should be achieving.

Community care has many declared aims: promoting independence, helping people to achieve their full potential, giving users choice and more control over their lives, supporting carers. Do users and carers agree with these aims? What else do they expect from services? Do different groups have different expectations? Greater clarity about the objectives of services will assist those who plan and provide services, as well as those who use them.

**Involving users in examining outcomes**

Assessing the outcomes of services for individuals calls for the involvement of users. The new community care arrangements aim to give users and carers a greater individual say in how they live their lives and the services they need to help them do so. They must also have a say in assessing the effectiveness of those services. After all, users are best placed to say what difference services have made to their lives.

Opportunities for users to have a say in assessing the impact of their services include reviewing, with a care manager, the outcomes of their care plan, or taking part in a review of a particular service.

**Routine monitoring**

As yet, there are no easy-to-use, routine methods of assessing the outcomes of services. The yardsticks for measuring what has been achieved need to be acceptable to social services professionals, to users and to carers. And practical methods need to be found which do not place too heavy a workload on those involved.

**What’s in it for users and carers?**

- Contributing to work on the outcomes of community care services is an opportunity for users and carers to influence what is provided.
- It is a chance to clarify the purpose of services so that users know what to
expect and can themselves monitor the performance of services.

- Services which measure up to criteria set by users will be more effective in meeting needs.

**What’s in it for professionals?**

- A set of easy-to-use methods for assessing outcomes will help professional staff tell how far they are meeting users’ needs and if alternative or additional services are required.

- Routinely assessing outcomes will allow agencies to use their resources in the most effective way.

**Our programme of work**

- A review of ways of looking at outcomes for users and for carers, as described in the literature

- Discussions with social services managers about the possibilities for examining outcomes in routine practice

- Seminars with researchers to bring together current knowledge and research findings

- Consultation with users’ and carers’ organisations - at national and regional levels

- Two research and development projects at a local level examining outcomes for:
  - Older people and carers of older people
  - Younger people with physical impairments and carers

- Taking as the starting point discussions with service users and with social services staff, and working towards the development of practical ways of assessing outcomes in everyday practice

- Other work identified by social services departments, users or carers.
APPENDIX 4
ORGANISATIONS TAKING PART IN THE STUDY
Age Concern Liverpool
Age Concern London
Age Concern Service Users' Action Forum (Wakefield District)
Age Concern Wiltshire
Arthritis Care (Wiltshire and Gloucestershire)
Association of Greater London Older Women
Beth Johnson Foundation
Black Disabled People’s Group
Brent Pensioners’ Forum
British Council of Disabled People
British Deaf Association
Camden Age Concern
Camden Forum of Elderly People
Carers’ National Association
Centre for Policy on Ageing
Clients Council for Older People (Sunderland)
Crossroads Association
Derbyshire Centre for Integrated Living
Disability Rights and Resource Centre (York)
Greater London Forum for the Elderly
Greenwich Association of Disabled People
Help and Care (Dorset)
Help the Aged
Islington Pensioners Forum
Lambeth Centre for Integrated Living
Mansfield Pensioners Action Association
Milton Keynes Centre for Integrated Living
National Pensioners Convention
Oxfordshire Pensioners’ Action Group
Princess Royal Trust for Carers
RADAR
Scarborough and Ryedale Carers Resource
Southampton Centre for Independent Living
Sutton Centre for Independent Living and Learning
Wandsworth Pensioners’ Forum
West of England Centre for Integrated Living
Wiltshire Users Network
Wolverhampton Pensioners’ Consortium
APPENDIX 5
REPORTS ENCLOSED OR REFERENCED BY RESPONDENTS
Age Concern London:

- Home Comforts: Home support for disabled older people, 1995
- Hospital Afterthought: Support for older people discharged from hospital, 1995

Age Concern Wiltshire, The Strategy for the Care of Older People in Eastern Wiltshire - SCOPE Project (summary and constitution)


Camden Age Concern:

- Social Welfare Service Specifications 1996/97, draft 2

Camden Healthy Cities (with Camden HealthLINK and Camden Forum of Elderly People):

- Camden Health News (1994 to 1996)
- Celebrating Together. 1993 in Camden: the European year of older people and solidarity between the generations
- European Year of Older People, and beyond… : Review of the Camden Healthy Cities Older People’s Health development Project, 1992-1995
- Kilburn Older People’s Safety Project: Interim Report, Older People’s Health Development Project, March 1994
- ‘Out and About’: Report of the older people’s local transport seminar 6 October 1994, Older People’s Health Development Project
- Who Cares for Your Health? A report of the older people’s community health seminar 17 June 1994, Older People’s Health Development Project
- Working Together for Health, Camden Healthy Cities Rev
- ‘Your Money, Your Rights’: Older people’s welfare rights information day 16 March 1995.
Carers National Association:

Community Care: Just a Fairytale? 1994
Better Tomorrows, 1995

Clients Council for Older People (Sunderland), Evaluation Report, 1995

Greater London Forum for the Elderly

Rowan Astbury, with Sammy Palfrey, Evaluation of the Project: The older voice in community care, Charities Evaluation Services, 1996

Greenwich Association of Disabled People:

Evaluation of Personal Assistance Schemes
Evaluation of Training Project (Independent Living Skills)
Greenwich Empowerment Project, by Jenny Morris, 1994

John Keep and Jill Clarkson, Disabled People Have Rights, RADAR, 1994

Gerry Mahaffey, ‘Hello! Is anybody there?’ Home care in Brent: past, present and future, Brent Pensioners Forum, 1995

West of England Centre for Integrated Living, Civil Rights and Special Needs, 1996