

Identifying stakeholder views about the outcomes of social care, and using outcome concepts in practice and user surveys

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Introduction

This paper will describe work, in progress at SPRU, designed not only to explore the views of different parties about the outcomes of social care, but also to investigate their opinions on how social care agencies could, or should, collect and use information about the outcomes being achieved for service users and their family carers. This focus on outcomes in routine or regular practice is a point of difference from the topic as described in the workshop invitation. The orientation of that paper seemed to be very much towards research, and the use of outcomes in research designed to generate a scientific knowledge base about effective interventions. Currently, an interest in outcomes is prominent in a considerably wider context than this.

Although the invitation to the workshop recognises that there are a range of interested parties who might define outcomes differently, it does not step outside the taken-for-granted framework of assumptions that outcome measurement is a good thing, in order to ask: who wants to measure outcomes, and why? In the social services context, and the context of Units working for policy makers, as many of us do, there are a range of agendas which include an interest in outcomes, but the primary concerns may be managerial (concerned with system control), or developmental (concerned with evaluation and change) rather than scientific (concerned to establish cause and effect). (See Qureshi, 1998, for an elaboration of this distinction). While all parties accept that a repertoire of scientific knowledge about the effectiveness of interventions would be useful, the question of whether research tools are useful and practical for agencies in the general course of their everyday work is by no means settled. Aspects of this were explored in a literature review conducted at the beginning of the outcomes programme (Nocon and Qureshi, 1996).

The second point of difference between our findings and the concepts outlined in the invitation is to be found in the definition of outcome. It is our argument that the definition given omits the idea of attribution, and, further, needs to be extended if it is to cover most of the activity which falls under the heading of social care or social services in the UK. Time limited intervention designed to make a difference between two points in time, while important, does not provide a suitable model for assessing continuous maintenance of an acceptable quality of life, nor for investigating those aspects of the process of service delivery which have profound impacts on the satisfaction of service users and their carers.

The SPRU R&D programme on outcomes of social care

Aims

The SPRU Outcomes Programme does not aim to construct scientific measurement tools for research purposes, but rather to investigate whether and how outcomes can be assessed as part of regular or routine practice, in ways that are practical and useful. 'Outcome' is interpreted as the impact or effect on the lives of service users or carers and the emphasis of the programme is on non-clinical, or social care, outcomes rather than health care outcomes. The phrase; 'part of regular or routine practice' means a continuing or repeated method which is a useful part of the regular activity of any agency providing or purchasing social care. Our work has concentrated upon local authority social services, although the approach could be used in any context in which social care is provided.

Background and Context

In the conference on Quality in Personal Social Services in Helsinki in 1996, Qureshi gave a paper which identified some of the barriers to the use of outcome concepts and outcome information in routine practice (see Qureshi, 1999). Fundamentally these revolved round professional and organisational cultures, which were not outcome-orientated, and the realities of practice in a system where resources were constrained and the creation of social care markets was the ideological agenda of the central government. There have been some changes since then, in all these areas, not least the emphases of central government since the election of the Labour government in 1997.

In funding a programme of work on outcomes the English Department of Health had a number of agendas, but prominent was a concern with issues of control and resource allocation. Interest in these issues has not faded. The concerns reflected to us by policy makers today include:

- Making a case for resources: Government Departments are required to demonstrate as part of a regular Comprehensive Spending Review that the money they receive is producing commensurate benefits, and, preferably, that further investment would produce greater returns. A lack of credible performance data on social services undermines the Department of Health (social care division) case to the Treasury.
- Modernisation agenda: the labour government has introduced an emphasis on restructuring existing institutions (local government, the National Health Service) to improve scope for influence of the public, and to raise standards and quality of services. As part of this, there are requirements to conduct surveys of users to determine satisfaction, and a duty on Local Authorities to achieve the best available quality or Best Value, which is backed up by new regulatory and performance assessment frameworks (Department of Health, 1998, 1999)
- There is a commitment centrally to development and use of a knowledge base for social care, and the Government proposes to set up a Social Care Institute of Excellence to support the use of the best available knowledge (Department of Health, 2000). However the SPRU programme does not flow directly from these latter concerns.

Methods

The user groups of concern in the SPRU programme were: older people, younger people (of working age) with physical or sensory impairments, carers. The staff were managers, care manager/social workers, occupational therapists, home care workers, day care workers. The questions were:

What are the outcomes of social care?

How should social services collect information about them?

“Outcome” was not a concept with which staff or users were familiar. We felt that we would need to use a deliberative methodology (Stewart, 1996) which allowed discussion and exchange of views between people. We did not want to use mixed stakeholder groups because part of our concern was about possible differences between stakeholders. Staff groups were kept at the same level of the hierarchy, to assist freedom of discussion and maximise participation. We attempted to be inclusive. We ran groups in sign language, groups using lip speakers and note-takers, groups in Asian and Eastern European languages, and groups conducted by telephone for people who did not wish to leave their homes. We used a range of methods to consult older people with dementia (cf. Bamford and Bruce, 2000).

Before commencing the projects, preliminary methodological work was conducted in order to find methods which would enable people to take part in discussion of outcomes, to think issues through and to exchange opinions. This work, involving focus groups of older people, disabled people and carers (nine groups in all) investigated a range of techniques for approaching the discussion of outcomes (Bagshaw and Unell, 1997). On the basis of this work, and our reading of the literature, it was decided to encourage deliberative processes by arranging for groups to meet on more than one occasion, and using vignettes, or individual case descriptions, as a basis for discussion in some

sessions. Group discussion was to be supplemented by a number of individual interviews which would enable some issues to be explored in greater depth, and would ensure that people who could not join a group discussion would not be excluded. However, even people who did not leave their homes were to be offered the opportunity to join a telephone discussion group - a technique which one team member, Patricia Thornton, had used successfully in a previous study. Deliberative group processes, for example citizens' juries, have become increasingly popular over the past two or three years as a way of obtaining the views of the public (Coote and Lenaghan, 1997), although their inclusiveness has been questioned (Barnes, 1999). Our experiences of attempting to use these methods left us with some reservations about the coverage, and possible bias that might result from use of group methods alone (cf. Patmore et al., 2000).

Techniques for consultation and recording varied as appropriate for different groups, and the majority of groups met on more than one occasion. Focus group scripts for work with users began by encouraging people to discuss their own particular experiences and the outcomes of services (both those they already experienced, and those which they felt should be achieved). Later in the discussion the focus was shifted to a more general level (usually by using a vignette or case scenario) to elicit views about outcomes for others. In relation to scenarios we deliberately invited service users to consider what the case study subject's life would be like, if services did their job well, in order to keep a focus on outcomes and prevent people from specifying the services they thought were needed. The nature of the scenario was varied for different groups. Finally, people (both staff and users/carers) were invited to discuss how social services could collect feedback from users, with probing on user and carer preferences, and ideas on who was best placed to collect information.

TABLE 3.1.1: BREAKDOWN OF NUMBERS OF PEOPLE INVOLVED IN THE RESEARCH PHASE

	<i>Service users</i>	<i>Staff</i>	<i>Carers</i>
Project 1 Older people	88	51	22
Project 2 Disabled people	39	41	8
Total	127	92	30

As indicated above, these groups and individual interviews involved 127 service users, 30 carers and 92 members of staff, with most groups meeting two or three times. When a suitable sampling frame existed, users were selected randomly. Otherwise they were recruited through nomination (of people meeting specified criteria) by staff, or recruitment in existing congregate settings such as day and resource centres. About half of those older home care users selected randomly were excluded because of cognitive impairment, severe illness, recent traumatic events (such as bereavement), or communication difficulties which would render participation in group discussion or interview impossible. Since we also conducted separate exercises to consult people with dementia, or functional mental illness, or who did not leave their homes, we feel confident that the views of these groups were sought, even if they were not included in the randomly selected user groups. However undoubtedly there are users whose views are difficult, if not impossible, for us to ascertain. In general we feel that we pushed the boundaries as far as we possibly could, given our resources and the time available. In total the consultation process generated material from 52 discussion groups and 45 individual interviews. All were taped and fully transcribed and subsequently analysed using computer-assisted qualitative data analysis. The team met regularly to discuss emerging themes and categories. The research questions provided an initial consistent framework for coding but this was elaborated as appropriate for the different groups.

Not everything worked as anticipated. Refusal rates for participating in groups were high among older people, and the likelihood of refusal increased with age. So strongly did our older respondents urge upon us a preference for individual interview at home that we abandoned one of our planned groups and substituted a set of eight individual interviews instead.

Findings

Staff views

From our work with staff we found a prevailing culture in social services in which few people make explicit use of outcome-related concepts in their day-to-day work, although managers are becoming increasingly interested. However, acceptance is growing of the right to demand information for accountability. There is also a belief that judging performance by outcomes would be more consonant with social work values, than judging merely by inputs or achievement of financial targets. There is undoubtedly scepticism and wariness about the possible uses which may be made of outcome information, and the ways in which it can be (mis)interpreted by the media and a range of actors in the political context. (The ways in which data on performance indicators have been handled would seem to justify some of that scepticism. Despite consultation and discussion with local authorities about the positive, preliminary and developmental nature of new performance indicator data, the first annual publication of national results in 1999 was accompanied by “naming and shaming” of a small number of local authorities where apparent deficiencies had allegedly been identified, even though these problems were sometimes trivial, and had not necessarily emerged from the indicators (Railton, 1999))

Some of the hopes which managers expressed for routine outcome information reflect questions about cost effectiveness and resource use which can only be answered by well designed comparative research (and perhaps not even then). In particular, information about the comparative effectiveness of different ways of providing assistance (eg direct payments compared with direct service provision), and about the benefits to be derived from prevention.

User views

Asian and Eastern European older people, and Deaf adults (who used sign language for communication) were the most concerned about access to services. Deaf people regarded themselves as a linguistic and cultural minority, who experienced discrimination, and this they had in common with older people from minority ethnic groups. Asian users had more positive experiences of local services, but nevertheless placed emphasis on problems of access and information. These issues were also mentioned by white (hearing) respondents but were not so prominent. Of course the question of access is logically prior to the question of outcomes. If few people can access services, then, even if excellent outcomes are achieved for them, the community is likely to regard the situation with concern. Formal organisations of users and carers, consulted earlier in the programme, had emphasised the importance of distributional outcomes which would reflect the degree of fairness and equity in the use of available resources. A programme of work which concentrated only on the impacts on people who actually received services would for them be deficient in addressing their concerns (Nocon, Qureshi and Thornton, 1996). At the time of writing the Government is due to issue guidelines on Fair Access to Care, although these appear to have been delayed for some months at present.

Much writing on community care, particularly for older people has concentrated only on what have been called destinational outcomes - whether or not the person remains in the community at home, or is admitted to some form of residential service (or dies). Certainly home care staff laid great emphasis on enabling people to remain at home as an important outcome of their services. In our view the location in which services are received is an intermediate outcome ie a change in the form of service provision, and not a final outcome at all. This is disputed by some of our colleagues who argue that the intrinsic importance of remaining at home is so great from the user perspective that many older people would see this as the principal aim of services. As a criterion of success we see some considerable danger in focussing solely on remaining at home. Rather we should be seeking to ensure appropriate admission to residential services. The appropriate time for admission is when the outcomes to be achieved by admission outweigh those to be achieved by remaining at home. This does not solve the problem of whose judgement is to prevail if opinions differ, but this is not a technical problem, it is a problem about securing an acceptable balance in individual cases between protection and preserving autonomy (Vabø 1996).

Models of outcome

In our early discussions with staff we had presented them with an intervention style model relying on measurement at time1, before intervention, and subsequently at time2, after intervention. Many people found this confusing, and could not fit this with the work they did or the results they thought they achieved. There are good reasons why this model is conceptually inadequate to reflect much social care activity. What emerged from our discussions with all stakeholders was a distinction between three different types of outcome, each implying a different model of measurement.

Maintaining Quality of Life

e.g. maintaining acceptable levels of personal comfort, safety, social contact, autonomy/control

Time Limited Change

e.g. improving confidence and regaining self care skills, reducing risk, improving access to the physical environment

Service Process Outcomes

e.g. service users feeling treated as a person, valued and respected

The meaning of each of these will be expanded below:

Maintenance

Intervention is often not time limited. It requires continuous input to maintain continued results, day after day. Despite the prominence given to change outcomes in health policy, improvements in health or physical or cognitive functioning are not generally the aim of social services, indeed in the majority of instances deterioration is to be expected, the aim of services is to maintain quality of life in the face of illness and disability. Managers estimated that as little as 15% of work was undertaken in situations where improvements in health or functioning could be expected, but this was “informed guesswork”. Broader evidence is thin on the ground, but Bauld *et al.* (2000) in a longitudinal study, found that 58% of a sample of 281 older social service users showed an increase in the number of health problems between time 1 and time 2, while only 18% showed a decrease (page 314). (Since these figures exclude 44 people who had died and 49 people who had been admitted to residential services by time 2 they represent an underestimate of the likely prevalence of cases in which deterioration in the persons condition is the context of service provision.)

Half of all assessments by social workers of older people are carried out in hospital, with the aim of devising a suitable care package to support them at home if possible, or deciding on an appropriate residential service. In these circumstances the aim of services is to prevent a hypothesised negative time 1 scenario from ever occurring. The scenario being prevented certainly is not (or should not be) available to be “measured”. Once the person is at home the definition of outcome here is:

“The difference between the client’s state or circumstances when receiving services, and their state or circumstances without services.”

This differs in two ways from the definition suggested for research in the Workshop invitation. It makes the importance of attribution explicit, an outcome has to be an outcome of services, otherwise differences not due to the intervention cannot be outcomes of it. Secondly, it allows measurement at one point in time to have significance in assessing success or failure.

Of course, determining attribution requires hypothetical judgements to be made about what would happen in the absence of services, but this is happening in practice all the time when decisions are made about actions to be taken. This definition shares with the “intervention” definition a lack of information on how to evaluate an outcome - that is, how to decide whether it is a good or bad outcome in the circumstances. To evaluate outcomes in the case of maintenance it is necessary to

compare the achieved state or condition with standards which reflect what public services are trying to achieve. That is, an explicit definition of the standards of quality of life which services are expected to achieve is required. For the purpose of deciding on whether further action is needed, all that is necessary is to compare the achieved standard with the desired standard. If there is a shortfall, and this can be remedied by actions within the scope of agency responsibilities, then these actions should be undertaken. This may be all you need to know for action decisions (is the person's quality of life at the acceptable level, if not why not? Can the shortfall be remedied by actions which are within agency responsibilities? If yes, what steps have to be taken?). However this comparison is not enough to decide how well services are doing, because social care is co-produced, that is to say because we have a mixed economy of welfare in which the statutory sector is but one provider. Hence the need to somehow ascertain how things would be without services.

Netten and Smith (1999) are developing a measure of social care outcome for older people, which embodies some of these principles. It focuses on maintenance only, and respondents (who may be older people, carers or staff, or all three - separately) are asked whether needs in relation to a specified range of domains of quality of life are being met fully, partly or not at all, and the extent to which needs would be met in the absence of services.

What were the domains of quality of life identified as important to maintain?

Perhaps inevitably, service users and carers took a more holistic perspective in assessing their needs and desired outcomes than workers operating in a particular agency are likely to do. Care managers' (social workers) orientation was closest to that of users, in that they saw it as their role to assist people in gaining access to other services or resources (such as benefits or medical treatment) which would help to meet desired outcomes that social care services could not meet, and they emphasised the importance of enabling the service user to talk through options, make choices and have a degree of control over their life. The outcomes which follow reflect a number of areas of quality of life. Although it has been argued that these are outcomes that usually have to be maintained on a continuous basis, it is recognised that the initial involvement of social services may sometimes be designed to achieve some change by first raising these aspects of quality of life to acceptable levels.

1. Meeting of basic physical needs ("keeping clean and comfortable")

There was consensus that services were responsible for ensuring that people who were not able to carry out their own self care were personally clean and comfortable, able to be clean and presentable in appearance, and to have enough to eat. Where occasional conflict was reported between older people and formal or informal carers over levels of personal cleanliness to be achieved this tended to involve situations where the older person had dementia or, perhaps, depression. In addition, there might be conflict over who should deliver the desired outcome, for example one disabled man reported being refused help with bathing because his wife was available to help him.

However somewhat more differences of emphasis between stakeholders centred round the ways in which these outcomes should be delivered, with users and carers favouring times of delivery which gave a normal pattern of life, and an unhurried pace, but services being sometimes unable to deliver this because of the problematic logistics of providing intensive services with peaks of activity in early mornings and late evenings. This is a widely recognised difficulty in achieving quality (Henwood *et al.* 1998), which has not been solved by transferring some or all demands to the private sector, who are equally vulnerable to the problems involved in dealing with such uneven variations in demand (Hardy and Wistow, 1997).

Conflict and disagreement was reported, particularly with carers, in situations where health and safety regulations or employment law meant that methods which the carer experienced as unnecessarily intrusive had to be used for lifting, such as hoists, or more than one member of staff. Again this is widely recognised as a problem (Eaton, 1997).

Finally, attitudes of staff assumed a particular importance in relation to personal care, with competence, kindness and sensitivity all valued. Continuity was often important to people who did not enjoy explaining their personal care needs over and over again to different people. However there was some individual variation in the wish for continuity, some older people enjoyed meeting a number of different members of staff.

Managers of home care services identified a need for a better understanding of service users feelings about the process of receiving personal care. This would be useful for training, and in organising services.

Of course bathing in particular has been identified as an area of conflict about provision between health and social care services. Debates in the UK about 'medical' or 'social' baths reflect each agencies imperatives to control or reduce expenditure, and have little relevance to service users or carers. Such disputes between agencies do not affect the legitimacy of the expectation that enabling people to enjoy personal cleanliness is an outcome to be expected from publically provided services. The Government through the 1999 Health Act and the NHS plan (chapter 7) have been attempting to ensure more joint working, pooled budgets, integrated services and structures.

2. Personal safety and security

Care managers identified the reduction of risk as an outcome they aimed to achieve, and alarm systems and regular visits from the home care service had one function of ensuring help in an emergency, or at least prompt discovery if anything untoward happened. The feeling of being connected to sources of help 'just in case' was important to those who received these services and would have been valued by some who did not receive them. Two older people expressed the view that if older people were expected to live alone and take care of themselves, even if disabled, then such assurance of help if needed ought at least to be offered in return.

Of course different people may have different perceptions of the degree of risk involved in a particular situation, and individuals may vary in the amount of anxiety experienced in the face of a given level of risk. People with dementia expressed particular fears about crime and personal safety, although this might be attributed to anxiety generated by the experience of their condition. In one staff group, a sceptical view was expressed that the intended outcome of some referrals was to reduce anxiety on the part of other professionals rather than the older person.

This outcome is demonstrably important in affecting decisions about entering residential care, not just in the obvious sense that care managers may feel that residential care is appropriate in situations of high risk, but also in terms of the important role played by subjective fears about safety and security in decisions made by individual older people to enter such care. (NHSE/SSI, 1994).

3. Being able to live in a clean and tidy environment

This outcome was of considerable importance to service users although many social services departments have substantially reduced the provision of cleaning. A degree of frustration was expressed by those who felt that the outcome of this lack of a service was lower standards of cleanliness than they would wish in their own homes. User's priorities were cleanliness of the kitchen and bathroom, although the state of the rest of the house mattered, and to some the state of the garden, particularly if it was visible to others. Discussion with older people suggested that while a clean and tidy environment was accorded importance in itself, dissatisfaction stemmed as much from the sense of no longer having control over the standards of cleanliness that prevail in one's own home, and from the public evidence, in the shape of a dusty home or an untidy garden, of one's incapacity to perform these everyday responsibilities.

Nationally quite a number of Departments have withdrawn from providing cleaning, either because it is considered as a less high priority, or because the advent of charging means that it can be provided more cheaply by the private sector. Users in the current study sometimes expressed

willingness to pay but given their vulnerability, felt wary of using the private sector when there was no recommended supplier. There have been widespread calls for inspection and accreditation in the domiciliary care sector, and clearly, if people are expected to secure their own services, even if they do have attendance allowances or other benefits to pay for them, such regulation would be of assistance to them in making choices. Regulation via the Care Standards Act (2000) is being introduced.

Some specific tasks that users wanted such as cleaning the inside of windows, curtains, and changing light bulbs were not performed by social services staff because of health and safety legislation. The range of specific tasks that people would have liked completing was quite wide. In general people wanted someone to assist them with those things which they would have done themselves if they had been able to do so alone. The specific tasks that they now required therefore depended on the nature of their impairment, and the things they would have chosen to do.

4. Keeping alert and active

This was seen as playing a role in preventing boredom and physical stagnation. People wanted to have something interesting to do, and somewhere to go. For most, this included opportunities to leave the house, although many of the older people's wishes about destinations were extremely moderate, for example to go window shopping, or see swans in the local park. This outcome was mentioned by care managers and by day care staff. Many of those who attended day care saw this as one outcome, although clearly such an outcome could be achieved in other ways: for example it could also be achieved through enabling people to continue to pursue existing interests or hobbies.

In common with many Departments there was some doubt at management level about the relative importance of this outcome in the context of reduced resources, and some uncertainty about the overall effectiveness of day care in producing the preventative effects which were claimed for it, although there was no doubt that service users valued the service. They certainly felt that day services had a positive or preventative effect on morale and mental health.

5. Access to social contact and company

People experiencing illness and disability and hampered by lack of access to transport often had much reduced opportunities to meet people and to socialise. Company and contact was often cited as a beneficial outcome of day care, both by users and staff. It was argued by older people that this made periods spent alone more bearable, warding off loneliness and perhaps even depression. While people did often enjoy their contacts and relationships with home care staff, this was not the same kind of company and contact with equals that meeting other older people could offer. Older people using day services emphasised the mutual support which they were able to obtain from each other, although this did not mean that they did not also value opportunities for contact with younger people.

In addition, some people wanted more contact with particular individuals (usually relatives), and found themselves unable to achieve this without assistance. For some this would have been more highly valued than attendance at a day centre. Similarly, some older people wished to continue to meet with people with whom they had common interests - one older man attended a history club for example.

Reducing isolation was widely recognised as one outcome services attempted to provide, although in general the function of social services was only to respond to this need in cases where it was a consequence of illness and disability. Day care for purely social reasons was increasingly seen as the responsibility of the voluntary sector.

6. Being in control of your life

This aspect of quality of life has been inferred from the discussion about ways of delivering the other outcomes and the role of services in achieving them. The issue of control arose particularly in relation to the meeting of physical needs and cleanliness and order of the immediate environment. People wanted to be able to plan and organise their days, and enjoy a normal pattern

of life. They wanted to maintain their own standards of cleanliness and tidiness in their own homes, to feel securely connected to the world and to avoid boredom and isolation. They wanted to be able to have and deploy resources to achieve these outcomes, including having access to maximum levels of benefit to which they were entitled, having sufficient information about services and entitlements to make choices, and being able to choose whether or not, and when, to draw on family assistance, or to give care to others. For people with dementia, the desire that life should be under control was not lost, but where certain activities of daily life, such as managing finances, were becoming a struggle, people valued being able to place them in the hands of someone they knew they could trust.

There was considerable commonality in the dimensions identified by older and younger disabled people, and, where there were differences, these largely reflected differences in life cycle expectations, for example younger people identified access to employment and active involvement in parenting as important, whereas older disabled people did not. Carers attached importance to the quality of life of the person they cared for, to their own quality of life and to the impacts (positive or negative) of the caring role.

Care managers were the professionals who discussed control at most length, and who saw themselves as responsible for assisting people to understand options and choices available to them, and to deal with new and difficult circumstances which might follow illness or accident. They placed more emphasis than users on the aim of coming to terms with the onset of illness or disability, of finding ways in which to make a situation tolerable or bearable, and enabling people to come to a more positive attitude towards the future. For home care workers, enabling people to live (or die) at home if this was what they wished, was defined as in itself enhancing the control exercised by older people. Home care managers, whose role was to sort out disputes or complaints (and to keep home care services within budget limits) were the most likely group to emphasise the degree to which some users and carers had to compromise, or accept services which might be less than ideal.

The achievement (or otherwise) of maintenance outcomes can be assessed at any given point in time by checking whether the person's state (currently and retrospectively) meets a defined acceptable standard. Defining appropriate standards is ultimately a political rather than a technical matter.

Time limited interventions and change

Of course the change/intervention model does apply to some social care activity, for example to assisting older people to recover confidence and skills after stroke or heart attack, or to modifying the environment to improve mobility. Services may help to achieve the quality of life outcomes directly, or may tackle problems which stand in the way of doing so. Some of the specific changes which services might try to bring about include:

- Reduce risks posed by dangers in the physical or social environment
- Improve ability to get around, inside and outside the home - there are many ways to achieve this: adaptations to the building, alternative housing, equipment, physiotherapy, mobility training for people who are blind, accessible transport.
- Reduce (or manage) symptoms of ill-health: e.g. pain, or lack of sleep, or "nerves" (everyday language for mental health problems such as anxiety and depression), or incontinence. A whole range of ways exist to achieve this, depending on the condition or illness the person is experiencing. Medical or health intervention may be required but, for example in the case of family carers, this may not be so. Services in the home, or behavioural interventions, or a "break" may help reduce symptoms.
- Improve communication: where communication between the person and others is hindered this may be improved by a range of methods, depending on the cause. For example availability of interpreters, training staff to use sign language, using audio tapes or braille, reading letters for people who are blind, hearing aids, speech therapy.

- **Regain skills and confidence:** after illness or accident, recover the confidence to deal positively with changed life circumstances, and/or personal and societal attitudes towards ill health and disability. This may happen as a result of natural recovery, and/or may involve assistance in the form of emotional support and counselling, training, physiotherapy and other rehabilitation services.
- **Improve family relationships:** through counselling, mediation, family therapy, providing “breaks” or other support to carers.
- **Improve benefit income** - maximising available income increases people’s control over their lives, and their capacity to make choices.

The list is potentially infinite, although in fact certain interventions will be much more frequent than others. Change outcomes generally reflect attempts to tackle problems or remove barriers which stand in the way of achieving desired levels of quality of life. The achievement of change outcomes has to be measured or assessed by looking at differences between two or more points in time, and by comparing achieved changes with those expected or anticipated when services were provided. The time-limited intervention model applies here.

Service process outcomes

These outcomes reflect intrinsically valued aspects of the way in which services are delivered, and are relevant whether the intention is change or maintenance. Much of the available evidence indicates that user satisfaction, or lack of it, is related at least as strongly to the way in which services are delivered as to any specific impacts or changes which may result (Harding and Beresford, 1996). The effectiveness of social care services cannot be reviewed without some evaluation, either subjective or objective, of the impact of the way in which services are delivered. For a convenient shorthand these will be referred to as ‘service process outcomes’. They are not attributes of services such as reliability or continuity, but rather they are the perceived impacts on users of the process of service delivery, for example, a perception that one is, or is not, ‘being treated as a person’. A range of process-related objectives are of key importance in relation to social care. These are important either because of their close relationship with the achievement of quality of life outcomes already listed, or because of their impact on the feelings and satisfaction of people receiving services. These process objectives by their nature should be continuously achieved, rather than achieved at, or by, a particular point in time. The overall impact on feelings desired is that the recipient of care should feel treated as a person (ie an individual), and as a fellow human being, and a valued citizen. The two main themes we extracted from our discussions reflected: the nature of interactions and relationships with staff; and the degree to which services, and the way in which they were organised and delivered, fitted well (or not) with the way in which the service user wished to organise their life.

The process objectives are:

1. Valued and treated with respect

This involves conveying a belief that someone has a legitimate right to services, that they are a valued person despite their difficulties or symptoms (this was particularly emphasised by people with mental illness but applied to others too), and maintaining confidentiality and privacy. An important aspect of this, mentioned by older people from minority ethnic groups, was respect for cultural and religious preferences and requirements.

2. Treated as a person

This is seen as having two aspects, one emphasising the uniqueness of the individual, and the other resting on the quality of interpersonal interactions with staff. The first involves a recognition of, and response to, differing individual needs and preferences. In relation to the second, some personalisation of staff attitudes involving at least a degree of warmth and friendliness was valued although friendship was not expected. Again there was individual variation in what older people preferred. Some older people attached greater importance to the completion of the required tasks than to conversation or friendliness, and found that some staff spent too much time talking. There was some discussion in staff groups about the degree to which home care staff should develop

relationships with older people, with some feeling this was a valuable part of their role, but others seeing it as frowned upon, and a potential source of difficulties.

3. *Value for money*

This was a relatively new issue brought onto the agenda by the introduction of charging for services. The charging policy was in its early days and apparent inconsistencies emerged in group discussion. Some people had refused services because of the cost, or because they thought value for money was poor. In the absence of services they used private commercial sources, family members or somehow managed without assistance. However, those who paid did make observations about value for money, and the fact of paying did seem to increase people's perception that they should have more say, about the tasks which were performed, for example.

4. *A 'good fit' with existing care giving and receiving within the family*

People wanted services to be delivered in ways that would fit in well with their ideas about appropriate roles for family members. Their preference was that whether or not care was given by family members should be a matter of choice, with people receiving support in providing care if that was what they wished to do, and being enabled to access sources of help other than the family if they judged the costs of giving or receiving family help to be too high. Specific outcomes identified by carers are listed separately below. There is no intention here to suggest that older people and their families would always interpret this outcome in the same way. Indeed, negotiating an agreed path through differing ideas about who should provide assistance could be a complex undertaking. However satisfactory interweaving of different sources of care was an objective to aim for. People did not enjoy feeling that they 'had to' rely on their families and wanted services to have appropriate or reasonable expectations of families. In this context Asian elders had encountered a lack of understanding on the part of some service providers, of their concerns about the difficulties for unmarried sons who became involved in giving care, and of their expectation that daughters, once married, would be unable to continue to provide care for their parents.

5. *A 'good fit' with cultural and religious preferences and requirements*

This embodied a whole range of detailed issues, which varied for different groups, but which were sufficiently important for people to indicate that unsuitable services would not be acceptable. Issues included the way in which domestic tasks were performed, as well as staff characteristics, language skills and the provision of appropriate food and activities. As mentioned, an understanding and acceptance of the ways in which family obligations operate in different communities would contribute to achieving this outcome.

6. *User 'has a say' in services*

In order to achieve outcomes 4 and 5 above, and desired levels of control over their life, people wanted to be able to influence, for example, the time and the pace at which tasks were done, the days on which services were used, the choice of staff who worked and the particular work which was done when home care services arrived. Information about possible options, and the opportunity to discuss this with a knowledgeable person, were important ways of facilitating this.

Recently rules have been changed to allow older people to receive direct payments instead of services. This was not possible at the time of our study. It will be of some interest to see the extent to which this option is taken up and used by older people who wish for more control over the assistance they receive.

Service process outcomes reflect impacts of the way in which services are delivered, and can thus only be assessed or measured (at one point in time, and retrospectively) after at least some services have been delivered to the user. The finding that such outcomes are of importance to users and carers reinforces the view that the impacts of process can be as important in generating user satisfaction or dissatisfaction as other outcomes. This view has often been expressed in research by, and with, service users and carers (Harding and Beresford, 1995; Turner, 2000).

Using the framework in practice

This framework seemed to us meaningful for describing the bulk of social care activity because, while acknowledging that changes or improvements were being sought in some instances, it emphasised that much activity was directed towards continuous maintenance. The second part of our programme involved finding ways to introduce these concepts into the day to day work of agencies. After conducting this work we took the view that outcome information could not currently be extracted from agency case records, or management information. In the longer term, the introduction of an outcome focus into routine procedures such as assessment, care planning and review would be an essential first step before data from such procedures could potentially have value in investigating outcomes. We decided therefore to attempt to do this.

The only way to collect such information in the short term would be through separate collection exercises such as user surveys. Certainly users were keen that information supplied by them was a key part of any evaluative exercise. We as researchers had considerable interest in user preferences between different methods of data collection. Service users proved willing and able to give us their perspectives on the relative merits and demerits of different methods, however it was also made clear to us that this was not the key issue for them. The key issues were: who would see the information and what would they be able to do about it? Their emphasis on these issues was a useful corrective to our emphasis on methods, reinforcing the importance of interpretation and action as essential in completing the feedback loop required in order that the time and effort spent in data collection does not ultimately prove fruitless (Smith, 1996).

(Paper 2)

The development projects

Five different possibilities were selected for development on the grounds that they were potentially adoptable in the current policy and practice context. Three projects concerned changes to care management, and two involved separate collection of outcome information directly from service users or carers. The projects are listed briefly below:

Outcome focus in care management

Assessment summary project: developing a brief summary of intended outcomes for older people, and their carers, which could be integrated into local assessment procedures.

Briefing sheet project: developing and implementing a briefing sheet for home care providers to remind them of intended outcomes and user preferences, and integrating this into routine practice.

Outcomes for carers project: developing and testing a research-based focus on outcomes for carers into assessment, care planning and review for carers.

Separate evaluative exercises

Interviews by managers: a programme of 'customer visits' in which senior and middle managers interviewed a sample of social services older service users, using an outcome-focussed schedule.

Survey of service users and carers: implementation of a rolling postal survey of adult users of an occupational therapy assessment, equipment and adaptations service, designed by a mixed group of stakeholders.

The projects were conducted in partnership with two social services departments and have clearly demonstrated that the inclusion of outcome ideas and concepts is possible in care management with older people and carers, as well as in surveys or 'customer visits'. In each instance the outcome ideas were modified, simplified and adapted to fit local ideas about good practice, and local procedures. Workshops, training and briefing ensured that staff were able to understand and discuss the concept of outcomes and how it might be applied to their work. The involvement of users and carers, both in the initial research, and in the various development projects, gave the work credibility in the eyes of staff, as well as enhancing its relevance to service users and carers themselves. The projects are further described below.

1. Incorporation of an Outcomes Focus into Care Management

The intention of the work on care management is to provide a clearer link between assessment and care planning by being explicit about the outcomes which services (and other sources of assistance) are aiming to achieve, and by ensuring that specific user or carer preferences or priorities are made explicit and met, as far as is practicable. The SPRU development work in this area took the form of three projects; assessment of older people, separate assessment and review of carers and provider briefing in home care.

A) Assessment of Older People

The aim of this piece of work was to develop a tool which could be used during a care manager's assessment to ensure that those outcomes intended to be achieved by services, and the preferences of service users and carers, can be summarised and incorporated into the care plan.

The development process consisted of five meetings of a (local) working group which looked specifically at the assessment process for older people; two workshops for 17 staff who undertook assessment in which the outcomes frameworks and proposed tools were introduced and a pilot study involving 30 assessment by 12 members of staff in which the tools were tested in assessments of older people.

The documentation that was developed comprises an outcome summary, which is a one page form containing six headings, and a prompt list of commonly identified outcomes to assist in the

summarisation. The outcomes framework, at the request of staff, was embodied in this prompt list which staff could use as an aide memoire when constructing a summary of intended outcomes. The summary form integrates the consideration of intended outcomes with ideas about good practice in assessment. As well as considering outcomes directly, the summary also requires information to be recorded on anticipated changes (in the person's condition or situation), which might affect service delivery; options considered for achieving outcomes; and user and carer preferences or priorities in relation to service delivery. Assessors then have to state their conclusions. The summary provides an underpinning for the subsequent care plan. Care managers working with older people reported variously that the use of the outcomes framework and the new summary form: helped to focus the assessment; made the rationale for the support provided clearer; helped to put risks in context; and provided a more positive way to share the assessment with users than by focussing on 'needs'. The framework was welcomed as consonant with social care values. Managers welcomed the clarity achieved, which they considered would aid performance management. In addition, they saw the outcomes framework, once established in use, as a potential basis for aggregation, and plan to test this in practice.

B) Assessment and Review of Carers

This project aimed to develop tools which would encourage a more systematic explicit and participative approach to carer assessment and review. The approach was developed collaboratively with carers, front-line staff and managers in one local authority. Some existing research-based instruments were adopted and adapted to the requirements of the project (Nolan et al. 1998). Also new tools were developed, such as the range of self-completion questionnaires for carers. 14 practitioners tested these tools during assessment of 37 carers and 15 subsequent reviews.

This outcome-focussed way of working was welcomed by staff and managers involved, and was seen, once it had been practised, as a significant culture shift with benefits both for users and carers. For example carers felt recognised, 'listened to', and were enabled to reflect on their needs; care plans were often targeted more effectively towards individual outcomes, priorities and preferences. Feedback from carers supported this, although they had not necessarily recognised the use of pencil and paper questionnaires as part of assessment, or as designed to help them identify areas to be addressed, even if this was the result. Although overall the tools were regarded as an undoubted improvement in practice, the more distinct and systematic focus on carers was more time-consuming, and would clearly require more resources. New ways of working had to be supported by allowing adequate time, and this was limited by the volume of assessments of older people which had to be undertaken. Trigger questions were developed as part of the assessment of older people in order to assist decision making about when more intensive work with carers should be pursued, and when it should not. The potential for collecting aggregate information about outcomes for carers was also demonstrated.

C) Provider briefing in Home Care

In this project a tool (the 'briefing sheet') was developed which enabled staff providing home care to see clearly the key facts concerning the service user's situation. The briefing sheet communicates individual priorities, special requests or needs, changes to work for or watch for, and intended outcomes of services, to home care staff who were working with an individual. Use of the sheet was tested in a prototype home care record book which was kept in 27 service users' homes. After post-trial modifications, it was incorporated by Social Services as part of their general service and will be introduced to all new clients' homes during 2000 in the local authority area.

One considerable benefit of the briefing sheet is that it alerts staff to service user's unique requirements and their individual health vulnerabilities. Given that the numbers of older people receiving intensive home care are rising (now assessed to be at a third of the home care receipt population, Carvel 2000) yearly, such information is invaluable in considering levels of vulnerability and making difficult decisions concerning reasonable assessment of risk.

Home care assistants found it helpful, particularly for new staff, night staff, those who had been away for a while, and for users who had larger numbers of staff assisting them. The process of eliciting priorities proved able to uncover preferences which had not been previously articulated, as well as those which might have arisen since initial assessment. Clarity about outcomes helped to inform staff activity, for example older people could be prompted about physiotherapy exercises. Different home care teams varied in the extent to which quality-related preferences could be acted on, and this in itself generates interesting questions about organisational responses to individual variations in the aspects of quality which are important. Potentially the briefing sheet could feed into provider reviews, and, of course, the principle of a briefing sheet can be extended to providers other than home care, who have complained in studies conducted by the Social Services Inspectorate, about the paucity of information they receive from assessors (Goldsmith and Beaver, 1999).

2. Collecting Outcome-focussed feedback from service users and carers

The SPRU development work in this area took the form of two projects; a programme of service user interviews by service managers and using a postal questionnaire to collect information on outcomes from service users and carers.

D) Service User Interviews by Managers

This project was developed in response to views on the best means of collecting information on services given during the research phase by older service users. A programme of home interviews was undertaken with a random selection of 30 older service users and the 11 interviewers were the managers who had direct responsibility for these services. The interview schedule which was devised in SPRU examined outcomes in various areas of daily living and interviewees' experiences of the impact of services.

Despite initial reservations, staff involved in these '*customer visits*' expressed an enthusiasm for the process, particularly the direct contact with service users who received intensive assistance, and who were generally absent from formal events involving public participation. Managers were inspired by some of the users they met, and reminded of some of the achievements of services which, on a day-to-day basis, could be subsumed by the more usual management task of dealing with those who were dissatisfied. All those managers who had taken part expressed an interest in continuing to do so, although they recognised that a variety of alternative ways exist to use interviews by senior managers in future, and these are currently being explored locally. There was less certainty about the changes likely to result from the exercise. Some individual users interviewed had experienced consequent changes, and some managers had acted on their own initiative to tackle more general problems which had become visible. However, the extent of influence on the wider organisation cannot yet be judged because changes and flux in local management structure have temporarily delayed formal consideration of the full report. Factors, which may reduce the potential of the method, are the temptation to devolve the work to less senior managers, and the need to find the resources required for analysis and reporting on the results.

E) Using a Postal Questionnaire to collect information

In this project a postal questionnaire was developed in partnership with the local Disability Support Service which is responsible for the provision of occupational therapy, assessment, equipment and adaptations. Three questionnaires were designed for: users receiving advice only, minor adaptations and/or simple equipment; users receiving major adaptations or items of equipment; and carers. A total of 274 questionnaires were sent out and the response rates were generally good (over 70%) suggesting that this may be a useful method for gaining service user and carer views on such services.

This project demonstrated that users, carers and staff could work together to design outcome-related instruments to collect evaluative information, although not entirely without tensions. Safety, ease and comfort proved to be important dimensions, and were investigated along with more general quality of life. Although over half of respondents who had received substantial

assistance reported that the service had improved their quality of life, a further third indicated that it had prevented their quality of life from getting any worse, thus indicating that 'preventing deterioration' can be an achievement in a considerable number of cases, even if there is no observable change. Feedback from staff indicated that the results of the survey were perceived to be useful, and the local intention is to continue to seek opinions using slightly revised instrumentation. As would no doubt be the case in many other authorities, the scope for interpretation of the data was restricted by the limited amount of information about individuals held in computerised records, meaning that links with information from assessment, and precise details of service inputs, would have had to be extracted manually from case records. Time did not allow this to be done. Although the team and managers involved wish to continue with this method of collecting information, and believe it represents an improvement over their previous practice, the question of finding the resources for continuing data processing and analysis, once SPRU is no longer involved, remains to be settled.

Conclusion

The concept of outcomes can be applied in social care, and is of practical use. As embodied in the framework developed in stage one of the SPRU research, the concept is consonant with social care values, and fits with ideas about good practice. Once the concept is demystified, staff can become confident in achieving clarity about intended outcomes, and can see it as a valuable part of their work. Managers involved see potential longer term benefits in building on this work to improve the quality of management information. Equally, the inclusion of outcome-related questions in surveys of user and carer views provides a useful balance to information solely focussed on individual ratings of satisfaction. While some staff may easily adopt an outcomes perspective, for many, opportunities for training, discussion and practice are important facilitators in achieving the culture change required.

The 'core' of the development work, from our point of view, was the explicit introduction of outcome concepts, and domains of outcome identified by users, carers and staff, into agency practice (either as an integral part of frontline practice or through surveys). The ideas were simplified, modified and adapted as they were made suitable for use in practice, nonetheless the essential ideas remain recognisable, and their practicality and relevance has been improved by being linked into developments grounded in concerns in existing organisational and professional practice. Whether the specific instruments and approaches developed here are useful unadapted to other agencies remains to be tested, although there has certainly been considerable interest from other departments, and professional organisations, in our work. Reactions so far suggest that the work has considerable potential for extension to other authorities, other user groups, and across health and social care boundaries.

All projects have progressed through the innovation cycle of initiation, planning and trial implementation. The briefing sheet for home care, which required minor adaptation to already planned changes, is now established as a part of routine practice, and the projects on outcomes in care management for older people, and for carers, are scheduled for integration within the relevant authority, followed by further trials and full implementation along with other planned changes to assessment. The future for the 'customer' visits in the local context is less certain, and the survey of disability support services users is expected to continue in some form. All projects have local enthusiasts, who wish to see them carried forward. However some of the barriers to implementation persist, for example the need to find resources needed for training, briefing, analysis and reporting, and the concurrent demands of the pace of other changes in policy and practice. The rapidly changing policy and practice context both helped and hindered progress towards implementation. The thrust and overall direction of policy changes relating to performance management and Best Value reinforced the importance of the changes which were being attempted. At the same time, the volume of work for managers generated by the need to respond to new initiatives and policies, undoubtedly reduced scope for participation in our proposed developments which were at this stage 'optional' in comparison. The extent to which this work is seen as relevant to the new changes, and supported as being in tune with them, will undoubtedly influence the establishment, and longer term survival, of these new ways of working.

In our view these projects offer effective means to negotiate, record and communicate intended outcomes for older service users. In addition, we have tested and developed a useful research-based set of tools for in-depth work with carers, which has wide applicability and offers considerable scope for improvement in much direct work with carers. In the current context, where it is increasingly important to seek user and carer views, and to act on them, the projects involving separate collection of information illustrate a practical way to expose managers to a systematic 'holistic' user perspective on outcomes of services, and give an indication of one way to improve on user satisfaction surveys, by including a jointly developed outcome focus.

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