Quality measurement: a user approach

Leonie Kellaher
University of North London

Taking a user approach is something that is talked about with increasing frequency in connection with a whole range of services. Nevertheless, it is still not usual for those who receive services to speak from their own perspectives with confidence that what they are saying will be recognised. The *Caring for People who Live at Home* Initiative aims to show how services may become more responsive to users. How are we to translate this aim into action, to make it work?

The study of users introduced here draws upon the accounts of people who have experienced services which are being developed and tried out within the Initiative. It has been framed within two broad contexts. First, to understand views of users and their carers receiving the new, Initiative-generated services in the context of their lives as a whole. It is important to acknowledge that services, however crucial, are only a part of people's lives. Secondly, to understand users' abilities to influence the services they receive.

The regulation of the quality of services which people receive in the privacy and seclusion of their own homes is of interest to providers, purchasers and users. The aims of the study of users which PSI has commissioned, and which is covered in a preliminary fashion here, can be summarised as follows:

To understand the views of users and carers on:

- the place of Initiative services in their lives
- the quality of these services
- the flexibility of these services
- users' and carers' ability to effect changes to the services they receive
- how Initiative services can fit with mainstream services
- to learn from users and carers how we might develop mechanisms for assuring quality in home care services

The interviews

Through personal interviews with 100 users of 19 of the Initiative services, in seven participating authorities, we are beginning to learn something of the impact of these services and of the ways in which they connect with existing services. Approximately half of the users interviewed lived on their own; slightly fewer than this number were actually seen on their own, with relatives and carers sometimes being present. In more than a third of interviews both user and carer gave accounts of their experiences of services. Not surprisingly, in over a quarter of cases, the users were unable to give much information on their own behalf and the carer became the main source of information. However, in all but a minority of instances, the user was present and contributed to the account of the way services were experienced.

The users

Two-thirds of users were women, a fact linked to the age profile of this sample. Approaching a quarter of these users were aged under 60 years, with around 40 per cent being users aged over 80 years, a high proportion widowed. A quarter of users were single people and nearly a fifth (17 per cent) were from minority ethnic groups. Half of the users owned their own house, with most of the remainder renting from the local authority or a housing association. A small group – fewer than a tenth – rented privately or were in tied accommodation. A regional spread was achieved as well as an urban/rural mix.

The Initiative services

The nineteen Initiative services experienced by the 100 users ranged from the entirely functional – such as installation of rails and ramps to make the home more accessible in physical terms – through to the kind of intensive, full-time, one-to-one arrangements required to support young people with quite high levels of learning difficulty in homes of their own.

A preliminary analysis of all the services which the user was receiving at the time of the interview suggests that three-quarters had needs associated with quite high levels of service input. This is not to say that the quarter who appear to have relatively simple packages of care did not have high levels of need. Interestingly, users with fewer services were those most likely to have received the Initiative service before any other services. So we may speculate that the Initiative link may have given access to, or information about, other services.

> I must say that since coming to do ... they [SSD] have been very kind. I feel I can ask for anything that would help me. I feel they are approachable, I know a bit more ... I thought services were for people you know ... in debt

The three-quarters of users who had moderate or very complex care packages were likely to have had the Initiative service added to the standard services. But the implications of these additions are very important in understanding the Initiative and its potential. Even where level of need had been recognised as high for many years, users gave accounts which suggest that, because they had never fitted easily into providers' categories, they had been cut off from services which *they* judged appropriate. For instance, a user, housebound and unable to do anything for herself, observed that:

> They (Initiative service) come out of kindness ... they tell me about anything that is going ... I don't fit any of the categories. I'm not old ...

It was clear that, although this particular Initiative service was not appropriate, at least in its current form, for this person, it had the potential for widening her access to other services.

Issues raised by users

A great many issues have been raised by the users in this study which have implications for the development of services in the independent sector. Some of them are presented here. Many more will be discussed in the main study report.

Personal and functional care

One of the issues which emerges throughout the study is the distinction between personal, nursing and functional care. It will not be a surprise that most of these service users did not make corresponding distinctions. For example, users requiring some personal care as well as practical help commented upon the way a particular service fitted with their view of things:

> They said, 'We don't put cleaning as a priority, we put caring more.' But someone's got to do the cleaning ...

It may be an irony that, in this instance, where home care has been defined and specified in a way that contrasts with many of the earlier home help services, a degree of inflexibility may be present which puts the service at odds with the user's specification of what is required. In a different authority, but with a home care service where the specification stresses functional rather than personal care, a user said:

> It is important to me really, you do know that your house is being kept tidy and that ... she said she'd do my washing. I'm sure the other home help would,

> but it never came into the conversation. She never once said – about washing. It makes you feel your home is not getting neglected – changing beds, I've no worries. She can do anything you require ... it feels different, it makes for a better relationship, more like a daughter – it feels better. She does only what you need ... Yes, she would help me get my tights on ... I presume so.

In this instance, where the home help service had been replaced by a personalised cleaning service, the user, whilst obviously well satisfied, and able to make comparisons with previous arrangements, was unaware of a contract restriction on the kind of assistance she presumed would be available. In both these instances, the home help service had evolved into a service which was both flexible and responsive to users' needs. These users, along with many others, had a conception of home care, however, which had boundaries which differ from those of the providers or organisers.

While setting boundaries for the scope of a particular service is an essential part of provision as well as of user expectation there should ideally be a consensus on where the boundaries are. These examples serve to illustrate the dislocation which persists between user and provider expectation. Other examples give some clues as to how the gap might be narrowed, at the same time bringing about a sharper focusing of effort and resources.

Delineation of responsibilities

Users and carers expressed anxiety where there had not been time to work out clear procedures for managing the complex set of relationships associated with receiving care at home. As just suggested, the providers have responsibility for defining the scope of the service being provided and also for managing its workforce. Users, carers and workers need to develop and maintain relationships of trust. The responsiveness of Initiative services was frequently demonstrated in the consistency and continuity – of personnel and approach to the task – which users described. At the same time, this complex set of relationships could be quite delicate as illustrated by the following account:

> A little thing, hardly worth mentioning ... when I need to change the time [of the respite care] ... I would first ask her if she is free then ... but the office said I should phone them first ... but it seems to be going behind her back ... and I don't want anyone else ... It's a bit awkward.

There was no rift between the people involved here, just an awkwardness arising from split loyalties. It was clear to the carer that re-arrangements could not be made exclusively between the worker and the carer because of the agency's wider responsibilities – to its workforce and

to other users – but it was not easy to see how the delicate interdependencies might be managed without an unhelpful and over-bureaucratic response. The carer, when prompted, came up with an answer that seems workable; that she and the worker discuss the practical possibilities and that there should be a form which they would complete and the worker would pass to the organiser. The agency would then decide whether the suggested arrangement was feasible. The potential for user input to situations like this was striking across the range of services under consideration here, and the value of drawing users into the development of services is clear.

Bureaucracies and organisation

There were aspects of bureaucracy to which users had become accustomed, and seemed happy to retain. At the same time, one of the features they appreciated about Initiative services was the personal approach associated with them. It is important to understand the place that users see for bureaucracy in the new services they are experiencing. The instance noted above shows how a bureaucratic device might strike just the right note for all concerned. For another user, however, the failure of a home carer to produce official forms for signature and receipts – using 'bits of paper' instead, was a cause for criticism, passed off generously as teething troubles. At another level of concern the carer quoted below feared that the new service might be in danger of seizing up or becoming less flexible than it had been at the outset:

> When it first started you could get help at short notice ... but it's not working out that way ... it's getting clogged up ... and yet again, the carer has got to fit in with the organisation.

Another aspect of the way services develop emerged where Initiative services were just getting into their stride, building up a critical mass of clientele and of workers. Positive signals could be picked up by users who hoped for a greater influence on the new Initiative services than that they had had with more established services. The parents of a child with learning difficulties said:

> It is local and flexible and we can influence it.

The dilemma which new services in the independent sector face in maintaining a workforce with enough slack to permit continued responsiveness while remaining cost-conscious was recognised and understood by many users. They were sensitive to and anxious about early signs that a degree of imbalance might develop. This sensitivity was frequently matched by a restraint on the part of users not to push for more than what they perceived as their fair share.

Users and carers in the larger scheme of things

Users and carers were very conscious of their place in the larger scheme of things and made frequent reference to others in similar situations or in greater need. It can be argued from the detail offered by these hundred informants that users are well able to gauge, often with greater accuracy than providers and organisers, the particular level of service they require at a particular time. Furthermore, even where the need for support was considerable, users could still point to areas where changes might be made which replaced quantity with quality, sometimes with resource savings, invariably with efficiency and effectiveness in view:

> No, two days a week is enough. (Carer on day centre care for user).

> Before, they [home helps] just did what they wanted to do ... I had shopping forced on me. I didn't need that ... I liked to go shopping ... this one deals with essentials.

> Because of ... [the at-home, sitting and taking-out service] we were enabled to stop looking for residential respite – had a lot of trouble with it because it never worked out – she got worse and worse. (20 hours a week respite at home compared to residential respite one week in eight)

> I understand the difficulties. We can give and take ... we have bought things ourselves, but it gets harder and harder. (user requiring a high level of personal care assistance)

Another user observed that she really only needed half an hour of help to get up in the morning, but had to have an hour as this was the minimum unit of care purchased and provided. There is little evidence among these users and carers of indiscriminate or grasping attitudes. They appear very keen to have just the quantity of service which meets their requirements, and they were equally keen to trade quantity for quality in services. Other explanations emerge to support the argument that users are not at all inclined to be greedy. Reticence in the face of clear need is well documented in the literature on take-up rates of services of all kinds. The users and carers in this study offer some insights as to how they weigh things up, despite all the pressures they experience. The following carer, past retirement age, knowing that her parent already needs more support, said, 'I don't like to ask for more, I'll wait till pushed', and went on to explain that, although pressure was building up – in terms of her own anxieties, she was holding off, until the day came when anxiety peaked and she would be able to justify, principally to herself, asking for more help. She was building up a bank of credit or justification. Resistance to asking for more than is necessary arises for other reasons. Most people do not settle for dependency with ease, and the following comment is not untypical:

> I still feel I never wanted to have help.

Rather more forcefully, others indicated that they could not afford to have their own routines threatened by outside help, however necessary and however sensitive that help might be.

> Help can be a help, but sometimes it isn't. It can alter things.

This adds up to a reinforcement of something that is already well documented, that users do not make greedy demands on care services. More importantly, it shows the degree to which users are able to discriminate between care which is essential and that which is peripheral. To take this further, many carers commented on the enormous benefit they gained from quite modest levels of support, for example from a sitting service, which was seen as high quality, having all the characteristics of flexibility and reliability:

> I can go out now and not bother ... I used to go out [for shopping] and not get anything and come home worried.

and

> There's not many people who would come and sit for three hours ... I can go out and have conversation with friends ... conversation has had it here.

> I feel lovely those two hours ... my mind is relieved.

Users, carers and quality assurance

The issues touched upon above are intended to illustrate how the user study has begun to show that users and carers can be very well placed to become much more critically involved in making judgements about services. It may not be possible to move away from the more traditional large scale approaches to service delivery which economies of scale dictate. Through an understanding of how users regard the Initiative services, however, it is possible to envisage where user contributions should be built in to the development and monitoring of new and existing services. There is some evidence to suggest that SSDs are looking at the workings of Initiative services and replicating some of the developments that are demonstrably filling gaps in provision for caring at home.

To conclude, the question of regulating the kinds of services which support people at home needs to be addressed. How might we develop mechanisms for assuring quality in home care services? A user approach to quality assurance suggests that those at the receiving end of services should be central informants and prominent assessors for services. There are two areas within the users' study where aspects of a regulatory strategy for home care services start to emerge.

Common themes emerged when respondents were asked what would be the best way of feeding information back to those who organise services:

- the need for some face-to-face contact with organisers
- the need for organisers to visit while the worker was in the home
- the need to report promptly on details of interest or concern

Review, in the longer-term sense, appears to be an important benchmark, but was not much emphasised by users. It is fair to suggest that, although many of these users are very preoccupied with the immediate term, they are by no means unconcerned about the longer term and the less local aspects of service provision at home. So, in considering how user-led quality assurance might be integrated into a regulatory system for new kinds of services, we should focus upon the day-to-day detail of experience at the receiving end of things. Clearly, though, such detail, if it is to become part of a system which regulates standards in services, has to be placed in a framework which is acceptable to those who organise, specify and provide services, as well as to users.

Users, carers, and making quality assurance work

In the course of interviewing users and their carers they would, often unprompted, produce the case notes which they held. These notes – sometimes quite lengthy and detailed – gave an account written by the worker of a particular session. Users themselves were often well acquainted with the contents and carers remarked that they felt that they gave them a good indication of what had gone on in their absence. The existence of such records was by no means universal, but their importance to users where they did exist suggests that a regulatory system might begin at this point, with an instrument which is comprehensible to users, which they hold, and which is an acceptable form for those who need feed-back at the level of day-to-day detail. Such a device could be a workable element in a system which is truly home-based. If the users' suggestion, that organisers visit while the worker is there – is systematically included, a structure comes into view which has a capacity to reflect, in a reliable and valid way, the nature of care at home which the Initiative-generated services are developing.