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Community care and independence: self-sufficiency or empowerment?

Abstract

In the UK there is currently a new focus on the basic purpose and objectives of services, not on organizational structure or the efficiency of the systems alone, but on the outcome of services for people who receive them. The Labour government has defined the promotion of independence as a priority for health and social services, but this outcome can be interpreted in a variety of ways which may not be compatible. As part of a programme of research into identifying ways of measuring the outcomes of community care, views about outcomes have been gathered from a number of stakeholders—disabled and older service users, family members and social service staff. This article outlines the views of disabled service users collected from both in-depth interviews and focus groups in a northern city. The article focuses on outcomes of services which they identified as important and considers the meaning of independence and the wider implications for clarifying objectives and defining service quality.

Key words: *autonomy, disability, outcomes, quality, social services*

Introduction

Despite the rhetoric of user choice, needs-led assessment and 'having a say in services' which imbued the community care reforms of the early 1990s, it has been widely argued that the core elements of Conservative government policy on community care were the desire to reduce the soaring cost of residential care, and the ideological commitment to the introduction of market principles into the public sector

(see Lewis and Glennerster, 1996). During the mid-1990s, monitoring of the implementation of community care was criticized by academics, service users and carers for being focused narrowly on systems and processes, and for relative neglect of outcomes for service users and their families (Warner, 1994; Wilson, 1995; Wistow, 1995).

In the White Paper *Modernising Social Services* (Department of Health, 1998) it is stated that the new Labour government's 'third way' for social care places the focus 'firmly on the quality of services experienced by, and outcomes achieved for, individuals and their carers' (para. 1.7). Such a shift of focus will be welcomed by many, but the White Paper makes it clear that considerable work remains to be done to achieve clarity about objectives of social care and the standards to be expected (para. 1.4). Clarity about outcomes will be essential if future monitoring is to address the impacts on individuals rather than merely the characteristics of systems and services.

Among the priority areas identified in the White Paper, 'promoting independence' stands out as the one most clearly linked to a specified outcome for individuals. Independence is an aim which many would endorse, although, as we shall argue, it can be interpreted in different ways, which may not always be compatible. The term is used in current policy documents as though it were unproblematic. The principal confusion of salience here is between independence as autonomy and independence as self-sufficiency. Writing about preferred outcomes for older people, Grimley Evans observed:

Autonomy implies the ability of individuals to live the kind of life they want. Independence implies not having to rely on other people. These are not necessarily the same thing. . . . Autonomy is a customer-based objective and independence is a purveyor-favoured objective because it implies lower costs. (Grimley Evans, 1997: 25)

Disabled people have defined the meaning of independence in terms which unambiguously reflect a concern with autonomy, rather than a wish not to use the assistance of other people. Barnes (1991: 129) for example has argued:

Independence does not refer to someone who can do everything themselves, a feat that no human being can achieve whether they have an impairment or not, but indicates someone who is able to take control of their own life and to choose how that life should be led. It is a thought process not contingent upon physical abilities.

The phrase 'independent living' has been defined and elaborated in an influential stream of research and writing, which makes it quite clear that the emphasis is on the right to receive support to achieve participation in ordinary life, rather than self-sufficiency:

The concept of independent living is a broad one, embracing as it does the full range of human and civil rights. This means the right to have personal relationships, to be a parent, the right to equal access to education, training, employment and leisure activities and the right to participate in the life of the community. (Morris, 1993: 7)

This perspective on independence carries particular consequences for the kinds of state intervention or activity seen as likely to carry it forward. Direct assistance to individuals is not of course ruled out, but action also has to be taken to tackle:

All the things that impose restrictions on disabled people; ranging from individual prejudice to institutional discrimination, from inaccessible public buildings to unusable public transport systems, from segregated education to excluding work arrangements, and so on. (Oliver, 1996: 31–3)

Employment is an obvious example where there has been some recognition of the need to remove barriers, exemplified by the Disability Discrimination Act (1996), as well as the need to promote a variety of interventions at the individual level, such as Placing, Assessing and Counselling Teams (PACT) (now called Disability Services Teams) and the current Personal Adviser Project. The White Paper on modernizing social services (Department of Health, 1998: para. 2.18) states: 'Employment is one of the most powerful pathways to independence'. In her social exclusion speech, Harriet Harman perhaps gave a clue to the meaning of independence in this context: 'Work is central to the Government's attack on social exclusion. Work is the only route to sustained financial independence' (cited in Lister, 1998: 219). Here then, self-sufficiency (in this case financial) seems to be the preferred interpretation. If paid employment is the passport to social inclusion for some disabled people, then other means will be required to ensure inclusion for disabled people who cannot work, cannot find work, or who choose to devote their energies and capacities to making whatever contribution they can to raising their children or caring for other family members.

The White Paper does not offer a clear single definition of independence. At one point, promoting independence is seen as helping

people to 'do things for themselves for as long as possible' (para. 2.12). Elsewhere there is some emphasis on routes to social and economic participation, which suggests a broader interpretation, closer to the idea of independent living, as does the proposal to extend entitlement to direct payments to older people. However, there are other signs in the White Paper of an interpretation of independence which not only identifies promoting independence with increasing self-sufficiency, but regards support which does not bring about improvements in individual functioning as somehow second rate. The otherwise welcome commitment to increased access to rehabilitation services is expressed in a way which suggests that social services should largely focus on changing individuals, and that maintaining or supporting someone whose health or functioning is deteriorating, or remaining stable, is somehow second best: 'Social Services must aim whenever possible to help people get better, to improve their health and social functioning rather than just "keeping them going"' (para. 2.11). This statement is repeated on the cover of the government's subsequent documentation on promoting independence through preventative strategies (Department of Health, 1999).

The inclusion of the word 'just' is telling in this context. Who could argue against the idea that improvements should be aimed for 'whenever possible'? But is the achievement of improvements in individual functioning the main objective in the majority of instances where people need social care services? We would argue that such a formulation of objectives runs the risk of denigrating the bulk of social care activity which aims to provide continuous support and assistance to people whose functioning is likely to remain stable, or to deteriorate. Maintaining quality of life to an acceptable level, and maximizing the degree of control over the way that life is lived, may be more desirable aims for an individual than improving self-sufficiency or 'getting better'. In this sense 'keeping people going' should not be viewed as a lesser aim. To see rehabilitation as only concerned with getting people better by improving their health and social functioning is a limited view which reflects a value basis tied more closely to medical than to social care perspectives, as does the emphasis on achieving improvements by changing people. After all, functioning may be improved by changing the environment—for example, making public transport, buildings, equipment and information more accessible for disabled people—rather than by 'making people better'.

This article discusses disabled people's views about outcomes and

service quality, so as to contribute to a clarification of objectives, by identifying some of the specific outcomes which they consider to be important, and to illuminate their interpretations of the meaning of independence.

Methods

The research on which this article is based is part of a programme of research on social care outcomes being undertaken by the Social Policy Research Unit at the University of York. The ultimate aim of the programme is to find ways in which social services departments can collect and use information about the outcomes of services for service users. The programme is focused on outcomes for: older people; adults (under pension age) with physical or sensory impairments; and people providing assistance for family members or friends. The first phase of the programme concentrated on identifying the outcomes considered important by service users, and by staff and managers. It was anticipated that the concept of outcomes would be unfamiliar to all of these groups, and this meant that it was unlikely that a research approach which relied upon immediate answers to structured questions would produce a thoughtful and considered response. We considered that it was important to encourage a deliberative approach, as advocated in the literature on democratic practice in the public sector (Stewart, 1996), in which people would have time for reflection and discussion, and the opportunity to learn from each other.

On the basis of early pilot 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 (up to three meetings were held), and by using cameos, or individual case descriptions, as a basis for discussion in some sessions. Group discussion was 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, or did not wish to, join a group discussion would not be excluded. 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; Barnes, 1999). Although the numbers of people involved may be small compared with larger-scale structured surveys, such methods have provided a convincing indication of public views on complex issues,

although it has been argued that such processes may tend to exclude groups who cannot easily take part, for example people who use social services. Service users taking part in the SPRU study were selected randomly where a suitable sampling frame existed, otherwise they were recruited through nomination (of people meeting specified criteria) by staff, or by recruitment in existing congregate settings such as day and resource centres. The programme as a whole included group or individual discussion with 127 service users, 39 of them adults below pension age. The detailed analysis and quotes given in this article are from two discussion groups and five individual interviews involving adults below pension age with physical impairments.

Participants living in a northern city were recruited in a variety of ways. First, we approached a representative sample of those who had taken part in a recent city-wide local authority survey on disability, and who had agreed to take part in further research. The original survey had attempted to include all disabled people who had used the authority's housing or social services since the formation of the authority in 1996. Using information collected by the authority on age, gender and length of time disabled, we drew up a profile of a group that would be representative of the population of disabled people who had been surveyed, and approached people in the relevant categories until we had recruited a group with a similar composition to the survey population. Because this resulted in the inclusion of very few people below the age of 40, we made separate attempts to recruit a group of younger people, since we thought it possible that their concerns about outcomes might differ from those of relatively older people. Posters were distributed at day centres and a college of further education, and opt-in letters were sent out to the users of the local personal assistance scheme, through the coordinator, which requested people to send in a tear off slip with their name and address if they agreed to take part in the research. Because a number of people were interested to participate, but preferred not to join a group, five individual home interviews were also conducted.

Profile of participants

The first focus group consisted of six women and two men. Three received home care (two from the in-house service, one from a private agency), four had aids and equipment, one went to the day centre, one had a family aid worker and another had an occupational therapist (OT). In the second focus group there were three people in their twen-

ties, one man and two women (one of whom was Asian). Two attended a day centre, one of whom also had equipment and adaptations, and one only had equipment.

The five participants interviewed individually were all women. All five had aids and equipment. Two were home care users, and one had help at home with personal hygiene. The three personal assistance scheme users consisted of two women and one man.

Outcomes and the meaning of independence

Users identified a number of outcomes, some of which were currently being achieved, and some of which they felt would, if achieved, enhance their quality of life. These included a number of linked outcomes related to the business of daily living such as personal cleanliness, a clean home to one's own standard, ability to move about freely at home and freedom to move about outside so as to maintain social contact and interesting activities. These were continuously underpinned by issues of choice, independence and control over one's life. Each of these are now discussed, with illustrative quotes from users themselves.

Personal cleanliness and comfort

Feeling clean and at ease with oneself was crucial when defining one's quality of life:

Quality of life is knowing that you're comfortable with yourself and that can be from getting dressed in the morning, washed, feeling that you're clean, you can then face your day comfortably.

There is often an assumption that if people are getting a bathing service then they are clean. However, the emphasis here is on the outcome for the user—'feeling clean' rather than the receipt of a bathing service. Quality standards relating to inputs, such as an all over wash once a week, do not guarantee the required outcome from a user perspective.

I need washing from top to bottom because I can't wash myself and I can't get behind to wash myself . . . I'm a big lady and I smell . . .

A substantial majority of participants felt that *a clean home to a self-defined standard* was very important:

The quality of life is knowing that the house is as (you) would like to keep it. There's nothing more frustrating than looking at something. I had a mirror installed in my bathroom and the dust from the wall fell below the sink level near the wall. Every time I went to the toilet I saw this dust, I couldn't reach it and it went on for three months before I realized I could get home help and finally I got this damn wall cleaned. It's keeping your house the way you want to and being comfortable in your own home.

Despite such feelings, a majority felt that cleaning was afforded a low priority by service providers. Consequently, some were forced to rely on family members who were themselves frail or unwell to help clean the house.

Being able to move about freely at home

Accommodation which is unsuitable for a person's physical needs can undermine their quality of life in several different ways. For example, a participant who had arthritis reported how she often slept downstairs apart from her husband due to the difficulty with negotiating stairs. Inaccessible accommodation can also compromise personal hygiene and dignity:

There's no toilet downstairs here. I don't go upstairs any more than I'm forced to but I leave it until it's too late then I'm dribbling all the way upstairs, and I have to change two or three times a day. I can't put any pressure on these knees at all so going upstairs is a real struggle.

Freedom of movement outside the home

Being able to go where you want and when you want was identified as one of the most critical factors in determining one's quality of life. One person reported that she had become virtually housebound since becoming impaired as she could not use public transport:

Accessible buses would be a big help since the injury to my back I've become a hermit. I stay at home all the time.

Others felt that although there were alternative means of wheelchair accessible transport available if required, having to book a week or more in advance undermined their quality of life:

You can't be spontaneous and say I'd like to go to such a place today.

Being able to go where and when they wanted was also linked to being able to pursue some form of hobby or *leisure activity*. This was felt to be particularly important for those disabled people who live alone and are unemployed:

To be able to follow some interests . . . so you don't just exist. You have actually got an interest in life whether it be tapestry or painting or whatever.

Similarly, *social contact and company* are valued because they prevent isolation and break the monotony of being confined in the home with nothing to do. For some older disabled people who are housebound and live alone, having a chat with their home help can be as important (if not more so) as the performance of the practical tasks, particularly as this is often their only form of social contact. However, it seems unfortunate if disabled people in such circumstances are forced to choose between the need for social contact and, for example, a more or less clean home to live in:

Talking for an hour to them is as important as making me bed is to me. . . . To me personally, it is more important with me not going out very much.

Disagreements about priority outcomes

The definition of outcomes regarded by service providers as reasonable to expect seemed to some users to be pitched rather low. Whereas personal assistance within the home was readily accepted as a need (even if the user valued social contact more highly), support for integrated living was often viewed as a 'want', and thus defined by service providers as illegitimate, as the following comment from a homecare user demonstrates:

There seems to be a split between needs and wants, days out are a kind of a want and you can really do without them. . . . I just feel that it's not unreasonable to have the occasional social event. . . . I don't think it's unreasonable to expect that, because it's something that non-disabled people wouldn't think unreasonable for themselves to be doing. . . .

Similar experiences have been identified in other studies. For example, Morris (1993) demonstrated how personal care was given precedence over social support in her sample of 50 disabled people.

Social support is equally important to an individual's quality of life as Priestley (1998: 665) points out:

Without support to travel, to pursue social contact and to take part in the life of their communities, many disabled people face a bleak future of isolation and segregation within the home.

For example, those attending day centres felt that this was the only way they had of breaking isolation and making contact with other people:

Well I was at home, I wasn't really doing anything. It's given me a little social aspect as well because without that kind of a service, there's nothing. It's looking at four walls basically.

In contrast, the opportunity to organize and manage their own support gave those using the local personal assistance scheme a greater sense of freedom to have an active and varied social life:

I've a very good social life now . . . I go for drinks, go to friends' houses, they come to me, go out to have a bite and I have a mobile phone so I can phone my PA for her to be here when I want to come back.

Control over services

Thus, for these individuals, independent living is about access to and control of a range of community-based services which enable them to identify and pursue their own lifestyle. The opportunity to employ people of their own choice to provide the assistance needed gave those using the local personal assistance scheme more control over their lives:

I have two personal assistants working for me and basically they can do anything that I need doing. . . . The advantage of that is that you pick somebody . . . I know who's coming, . . . it's a matter of choice and flexibility because, . . . if I needed extra hours, I could ask one of my PAs to spend a whole day with me if that's what I wanted from that particular day so it gives you more of a choice.

Having chosen one's own personal assistant is also highly significant when it comes to receiving assistance from someone in very intimate matters:

It gives you control over who's coming in because having somebody come into your home can be very difficult . . . it's less intrusive if you've

picked somebody and to have them doing very intimate, personal things for you.

Being able to choose the person who does the assisting was also viewed as being extremely important in relation to maintaining one's right to privacy:

It means that the things that I need doing, I can get done without feeling it too much as an invasion of privacy. I feel it's very much helping me to be independent. I did feel, when we first came to the realization that we really had to have somebody come in, that it was an invasion of privacy. It's really nice being able to choose somebody myself, who I wanted, when I wanted them to be with me, where and when I want them. And what actually I want.

These positive reactions to personal assistance schemes are not new. Evans (1998) argued that the flexibility and control that a personal assistance scheme provides allow those disabled people reliant on support from others to live their lives the way they want instead of having to fit in with the time schedules and restrictions of direct service provision:

We want to choose the time we get up, we go to bed, we go to the toilet. We want to be able to choose who gives us the personal assistance we need, how we receive it and where we receive it. In short, we want to be able to plan how we spend our time without the constraints of fitting into the existing care system. (Evans, 1998: 26).

Clearly, choice, flexibility and control over when and how support is provided is at the heart of maintaining quality of life, and, as summed up by one user in our study, an integral part of what is meant by independence:

I think the whole thing we're talking about is maintaining independence, being able to live your life the way you choose to live it.

Choice about sources of assistance was part of independence, for example people might prefer to receive services rather than be dependent on family or friends. Where services were inadequate to achieve desired outcomes, then people remained dependent on informal help, as the following example of a woman who needed assistance with washing herself demonstrates:

They still only come three times a week and in that hot weather I had some of my family come in to see to me and then I have a friend that's got a shower downstairs and her husband started coming and taking me

round for a shower, you know, so I'm still relying on people to help me outside as well as having somebody coming in.

Another participant reported the absence of assessment for her needs for the most suitable type of wheelchair for her specific situation, as a result of which she was still reliant on family members to push her wheelchair.

Attitudes towards self-sufficiency and autonomy

Staff did argue that there were individuals who, in their view, preferred to remain dependent, and to have tasks performed for them which they could have undertaken themselves. However, these instances were regarded by staff as exceptional. The general view from our discussions with disabled people was that they do not want to be passive recipients of services. Some wanted help if tasks took too long, and/or required too much effort. Others, however, preferred to do tasks themselves, whatever it took, and enjoyed the sense of achievement, self-worth and independence this provided. It has been observed by other researchers that disabled people want to be assisted to make a contribution towards the task in question. In short, they do not want to be done for but rather to be doing with their personal assistants, as the following comment of a disabled person from Priestley (1998: 664) illustrates:

When we do the housework I can't do all of it but I do some of it. ... When we wash up and put away, we do it together, I can't reach up to the cupboard and they do that. I do part of it. So they're assisting not doing for which is very important to me.

Having roles 'taken over' and being given no opportunity for participation, and no say in how things were done, could be a painful experience, particularly when the obligations of parenthood were involved:

You should get involved in whatever they're doing, like if it was caring for your children, you should be involved like sitting and talking while your kids are in the bath. I always got ushered out the bathroom so I never felt part of caring for them ... I felt like I was in the way.

The greater self-sufficiency which suitable equipment or adaptations could bring was undoubtedly valued. Growing confidence in one's abilities, and the reliability of help, could bring about greater

self-sufficiency and less need for help. However, as recounted by one PA user, intensive assistance in the short term could be a necessary condition for developing the confidence needed for managing alone, and continued self-sufficiency was underpinned by the assurance that assistance was available when the individual judged it was needed:

They've given me confidence, because to begin with I was taking one of my PAs on a five minute journey, just to be with me. . . . Because going out and crossing roads and getting up pavements on my own, was something I'd never had to do because my husband did all that for me with the wheelchair . . . so . . . even something like a five minute journey was a big step and it gave me the confidence so that now I feel that I don't always have to have somebody with me but if I do want them, then I can choose . . . it helps me to live here with the minimum of care and the minimum of intrusion and it's helped my confidence enormously so that I now feel able to go out more into the community.

Another user pointed to the variability of her needs for assistance, and the importance of help being available when she needed it:

I have a lot of carers coming in to see to me. I have one about five to eight in the morning and she . . . helps do things, you know, she gets me my slippers on, because I can't get them on . . . and then I get washed and if I need help to dry and put my clothes on. Sometimes I'm worse than others with the arthritis and if I'm stuck, well she'll help me.

The key factor in this is choice and control: being able to choose the occasion and degree of assistance required to enable the person to reach the outcomes they define as important in the way they prefer. Lack of control could cause people to refuse services:

We'd had some contact with home helps and I'd felt that as a big intrusion . . . they did things their way and I felt I had no control over it. It was easy in those circumstances to say, 'Oh no, this isn't working we'll just carry on, we're managing OK without them'.

Disabled people's views on quality

Definitions of quality from the perspective of those on the receiving end of services may be considerably different from those of professionals and service agencies. The earlier discussion of outcomes has a number of implications for definitions of quality from a user

perspective. Service users are more interested in what services can do for them, in the effect on their lives. They also emphasize that the way in which services are delivered—the extent to which the behaviour of workers is or is not empowering—is a crucial and necessary component of quality (Beresford, 1997). The definition of quality in service provision is value-led as Priestley (1995: 7) points out:

Definitions of quality (used to judge both disabled people's quality of life and the quality of the services available to them) are derived from and determined by a variety of dominant and oppressive social values about the role of disabled people in society . . . in this way the social construction of quality is inextricably bound up with the social construction of disablement.

Thus, any attempt to define quality must take full and proper account of the values of service users as Priestley goes on to suggest:

An approach to service quality measurement which takes into account not only the established criteria of outcomes and process but also the service delivery structure in terms of the degree to which that structure facilitates and empowers disabled people to improve their own quality of life. (Priestley, 1995: 17)

Participants were asked what made a good quality service and what a poor one. Poor quality services failed to deliver the outcomes identified, thereby undermining independence. An ideal service was identified as one in which people had a say in how things were done, and, if desired, had assistance to perform tasks themselves.

Having a say—control over services and meeting user-defined standards

Control over the people who might provide a service and over the timing of tasks were both important, because they affected the likelihood of satisfactory interactions with staff and the degree to which people could achieve their own goals, for example, could meet the standards of parenting which they found acceptable:

When I came out of hospital . . . the home help didn't come till half past eight (or) nine o'clock. But my children get up at half past six. . . . By which point [my youngest son] has gone a full night with a nappy on. It's just a general restriction all the time because you have to stick to set hours . . . it's just the lack of control that's the main problem.

The users have no part in the recruitment process for these people working for the agency. It's the lack of control. . . . If there is a major problem with a person, if you really cannot get on with someone then you can ring up the agency and say there is a problem and please don't send this person, there's going to be some upset, there's going to be an argument. I have done that on a couple of occasions and I've asked somebody to be sent less because I found that I could get on with somebody in small doses.

Competence

Competence was usually defined in terms of ability to achieve user-defined standards, being well-informed about the user's individual needs and ensuring that these were met. There was evidence of variable standards of home care, with some services being of an unacceptably low quality, for example, where cups were inadequately rinsed after being cleaned with disinfectant. There were particular concerns over the standards of domestic cleaning and cover at weekends and evenings.

Waiting times

Delays in obtaining needed assistance were criticized. Participants felt that the delay between initial request and assessment was too long, and were particularly concerned about the time they had to wait between assessment and the provision of equipment or adaptations. Such delays undermined their independence and sense of control over their lives:

I had to wait nine months for an electric wheelchair, I mean, unless there was somebody there I couldn't literally get from my lounge to my kitchen for nine months.

[L]evelling the ground and the toilet took 12 months or so. . . . The assessment was quite quick. . . . But the actual process of it going through, you know, whether I was going to be able to have it or not, that took a while . . . I think that expression . . . 'putting your life on standby', I think that covers a lot of people's experiences with social services.

Safety of work carried out

Others expressed concern over the seeming lack of attention paid to the safety of aids or equipment provided:

The rail is a big help but it's not very safe. I get a little bit frightened because since they put it up my son had to refasten it to the wall but it's still not very safe now, it's still a bit weak.

Such provision, far from promoting independence, is likely to undermine user confidence and self-esteem.

Information to support choice

Lack of information on what services are available is often cited as a barrier by disabled people to their achieving a range of opportunities and services (Evans, 1998). For example, Ellis (1993) found that prior to assessment most disabled people knew nothing of the help they could expect from social services, most had only learnt about services by chance and frequently *after* the information would have been most useful to them. As the old adage says, knowledge is power. Without adequate knowledge of services, individuals are powerless and dependent on the judgement of professionals. Not surprisingly, then, there is an overwhelming consensus among all user groups of the value and necessity for clear and accessible information so that they can make informed choices about what services will best meet their needs:

I think it's nice actually to know what they are specifically. Now I can assess better in my mind whether I actually want to use it or not, if I know what the thing out there is.

Most felt that they had no way of accessing such information. Therefore, it was greatly appreciated when on a rare occasion a social worker had listed all the options available:

She said 'Now let me tell you what we can provide you if you need it'. And she spelled out everything that I could, all the services I could get ... who to call and what to ask for. ...

The failure to provide basic information about the use of equipment could unnecessarily prolong dependence. For example, a wheelchair user noted how her wheelchair was delivered to her without any explanation for how to set it up:

They didn't even ring or anything. They just came and dumped it and I just didn't know how to even think of setting it up, it was only when a mutual friend came who has one that he showed me how to use it. ... The same thing happened to him but I don't think it's acceptable.

Value for money

The introduction of charges had undoubtedly concentrated people's minds on the question of value for money, and perhaps had the positive consequence that it led to less tolerance of unsatisfactory services. Value for money was inextricably linked with competence, achievement of desired outcomes and the degree of control users had over services. People felt that if they were paying for a service, it should be of an acceptable standard; they resented paying for a substandard service:

Well I actually had to end my private agency service for the same reason, being on income support. £4 plus out of your money each week was a lot of money to pay for somebody who did something so unprofessionally.

Value for money was essentially defined in terms of achieving user-defined standards:

Half the time you find somebody to do your ironing and my friend she'd have to come round and do it again . . . I got to the stage of thinking 'I am paying for this service. I felt awful phoning up and saying 'This person cannot iron' or 'This person cannot do this'.

Being asked to pay for a service even when it was not delivered was also an issue:

Twice they didn't turn up when they were supposed to and they didn't let me know either. So I was left without being washed and I still had to pay the full money and I was narked over that.

Participants were concerned that the introduction of charging for services might prevent people from taking up services they needed, and staff, in their discussion groups, reported instances where they felt that people had refused services which they needed because of unwillingness to pay charges.

Staff attitudes

People's perceptions of the quality of service they were receiving were, to a large extent, shaped by the attitude of the workers who provided the service:

I had a really terrific home cleaner, a really superb first class lady . . . first of all, I always start with the attitude because that's important, her

pleasant attitude. But also the fact that I only had to tell her something once, I didn't have to go and show her. With everyone else every week I had to go in the kitchen and get out the cleaning equipment. . . .

My family aide worker, she . . . dealt totally with my children on a one to one. . . . And by the time she came to leave, my children were heart-broken . . . because she . . . wasn't a family aide worker by the end of it, she was a friend. I mean I'd have trouble like I say with the home help shopping, she'd throw me in back of her car and whip me up shopping. And we didn't tell anyone we were doing it.

Similarly, the helpful attitude of a social worker prompted the following comment:

[S]he came every month, very cheerful, again very helpful, how was I getting on, did I need this, did I need that. . . . When I needed a home help she checked in twice that week to make sure that it had been arranged and that somebody was coming. And then the day after the home help had been she came by to make sure that they'd been there and that I was satisfied. She was wonderful.

In contrast were examples where staff focused too heavily on the impairment rather than the individual:

Sometimes they can be really negative about you, rather than having a positive approach. They don't see you as a person, they just see you as a disabled person not being able to do things . . . it used to undermine my confidence and I had very low self-esteem.

Undoubtedly, therefore, the single most important factor identified by service users in determining a good quality service was the attitude of those providing the service. As the following words of a disabled person cited in Beresford et al. (1997) demonstrates:

So often it is the style of the way services are delivered rather than the service itself which produces a quality service . . . the home carer who gets you up in the morning can do this in an empowering way which enables you to face the efforts of the day positively or in a way which means that you are dressed and ready but not psychologically ready.

Respect, dignity, being treated equally, trust and reliability were all identified as critical factors in how service users felt about the service they received. At their best, relationships with staff maximized choice and control, reinforced self-esteem and dignity, and made users

feel genuinely valued and cared for; at their worst, they could enforce dependency and passivity, erode self-esteem and be intrusive.

Conclusion

The White Paper *Modernising Social Services* states that the government will establish clear objectives for social services and create a clear expectation of the outcomes social services are required to deliver (para. 7.4). As part of achieving clarity about these objectives, the word 'independence' will need to be unpacked, and its constituent meanings explicitly considered.

The outcomes outlined in this article can be a basis for defining the objectives of social services for disabled people and can provide a basis for understanding quality. A quality service from a user perspective is one which delivers the outcomes users are seeking, both in terms of specific aspects of quality of life (such as personal cleanliness, ability to move around freely both in the home and outside, parenting one's own children and accessing meaningful activity and social participation) and also in terms of the important aspects of process (enabling people to have control over their lives, being treated as valued human beings with legitimate needs, being able to choose when to have, and not to have, assistance in relation to their personal goals and preferred ways of living). These outcomes can apply without difficulty to interagency activity; indeed inputs across several agencies may be essential to achieve them. The accounts of workers who did provide information for choice, and who did respond to a disabled mother's own perceptions of her needs, illustrate that the desired quality can be delivered through conventional services, as well as direct payments, but other accounts suggest that the commitment to promoting independence in the sense of autonomy remains limited.

We have discussed the difference between professional definitions of independence, i.e. self-sufficiency, and disabled people's definition of independence, i.e. autonomy and empowerment. Disabled people have defined empowerment as being in control of their life, and being able to influence others. This means being able to define their own outcomes and to have the services they need provided in a way which will enable them to achieve those self-determined outcomes. Despite the continued political rhetoric of giving choice and empowerment, services all too often continue to be delivered in a way which

disempowers disabled people in the lack of control and choice they are afforded. One such example is the continued lack of information on what services are available without which disabled people are powerless and remain dependent on professionals' assessment of their needs. A lack of information for choice has the consequence that what is provided is still largely dependent on a political, administrative and professional judgement of what is suitable and affordable (Beresford, 1997).

One exception to the rhetoric is the legislation to give people the option to receive cash to arrange their own support packages. This legislation (Direct Payments Act 1996) was long fought for by disabled people to enable them to have control over the nature, purpose and quality of the assistance they receive. The benefits of this system are clear. Employing their own personal assistants gives disabled people hitherto denied choice and control in being able to decide when to go to bed, when to get up, get dressed and who should assist them in that and how, thus giving them greater equality with non-disabled people and promoting independence in the sense of autonomy. At present, the requirement to make direct payments available is voluntary, although the government is considering making it mandatory. The numbers reportedly receiving direct payments are very low (little above 1000 according to figures in the White Paper). Thus, it is important to continue striving towards achieving high quality provision within mainstream services in order to provide a legitimate choice. Not all disabled people want, or feel able, to have the responsibility that goes with direct payments; neither should they be forced to accept them in order to live independent and fulfilling lives. At present, however, evidence from our own and other studies suggests that the minority who are choosing and managing their own personal assistants are more likely to feel that they are living independent lives. Thus, for disabled people independence is about equity and control over one's life and to a lesser extent about self-sufficiency.

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