

Integrated and fragmented care observed from two case studies

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Introduction

People who are using services will always be the best reporters of what and how services are delivered. Only service users can really assess how far the services they receive do match up to what is needed. The voice of the service user is powerful and direct. It provides a different perspective from the sometimes-complaisant view of the service provider and policy maker. But people who are offered services are not always knowledgeable about the alternatives and want the services to 'be there' rather than something they have to think about. There is, therefore, a role for the researcher, the observer and the reporter to find out what services are provided and what the consequences seem to be.

This article reports what I observed happened to two people I knew well, from the perspective of a passionately concerned bystander who happens to have been a researcher with an interest in social care. The aim is to give a pen picture of the way in which care can impact on individuals for the benefit of those who provide it, but not experience it.

The two 'cases'

The two examples I will use are of my mother and of a friend, whom I will call Jill, and her husband 'Jack'. My mother lived in mid-Wales and Jack and Jill in London.

Jack and Jill

Jill was a highly articulate, warm, intelligent person who was passionate about words and understanding what happened to people and why. She was diagnosed as having a malignant brain tumour in January a couple of years ago. I will pick up the story in May after which she had had chemotherapy, which had slowed the growth but not eliminated the tumour. She was on large doses of steroids. By May the effect of the tumour was similar to her having had a stroke, she was virtually paralysed down her right side and her speech had largely gone. There was a crisis of some

kind and she had to go to hospital where her drug doses were changed. Her condition then stabilised and a hospital place was no longer necessary. A hospice was suggested and she was moved into one with a high reputation.

Jill did not want to be in the hospice, she wanted to be at home. Although she could not speak clearly she communicated her feelings very directly by turning her back on visitors. Jack and her friends could not bear this and Jack arranged for her to return home.

Initially the hospice provided nursing care every day but this was a temporary arrangement. The hospice was in a different London Borough from the one in which Jack and Jill lived and their authority provided no financial support to the hospice. Residents in their area, therefore, could not receive services free from the hospice—as those in neighbouring, contributing, Boroughs could. Jill's care at home became the responsibility of the local authority Social Services Department. They have a duty to assess the social care needs of people living in the community and to provide appropriate services on a means-tested basis.

The care manager from social services visited to carry out an assessment. Jack, who had just retired from many years as a probation officer, reported that the care manager was the person nearest to having a nervous breakdown that he had ever seen. The care manager gave the impression that care provided by social services might not be reliable and would be expensive, because Jack and Jill would have to pay full charges. Not surprisingly, Jack was rather put off and decided to use a private agency. He had to locate possible agencies himself and negotiate all the arrangements. I recall that initially someone from the agency came from 2 to 6 pm five days a week.

There was also a Macmillan nurse who visited sometimes and I think had overall responsibility for co-ordinating the various services; a Marie Curie nurse who was there two nights a week as Jack felt Jill could not be left alone at night; and a district nurse who visited at most once a week. (Macmillan and Marie Curie nurses are specialists in cancer care, I think provided

by voluntary organisations.) Jill's GP worked part-time (he trained other GPs the rest of the time). The local authority provided a bed with a water mattress, the pillow end of which could be raised by an air pump. Jack became the manager of the household and the carer with 24-hour responsibility.

I visited my friends when I could and heard from Jack what was happening. As a visitor I was not asked to be involved in any care tasks, particularly any personal care such as toileting or bathing. What I observed was a friend lying in bed all the time. No attempt was made to help her sit in a chair at any time but I do not know whether this was her wish. I don't think she was bathed frequently and perhaps not at all. There was a hoist provided by the social services department but Jack found it extremely difficult to use. I think that he physically lifted Jill onto the commode when she wanted to use it, and I don't think he was given any instruction on 'safe' lifting. It was lucky he is tall and fit.

During the time Jill was at home there were constant anxieties about the 'security' of the care arrangements. People would fail to arrive on time, Jill did not always take to them and Jack was still being required to carry the weight of the day-to-day care. There was also a question of money. Jack and Jill had savings and reasonable incomes but this did not remove the anxiety of whether there would be enough money to pay for all the care that was needed. This was not an area that it was easy to discuss but I felt that Jack was taking decisions based on financial grounds rather than considering what would best help him. I think that the provision of the Marie Curie nurse was not charged. But the Macmillan nurse who managed the access to this service frequently talked of reducing it because of the shortage of resources. Her view was that Jill could always go into a nursing home.

Two particular incidents stand out in my mind where services were clearly not oriented to the needs of the user. The first concerned the bed. Jill was in bed all the time. Occasionally she tried to get out of it. But being paralysed down one side meant that she inevitably fell. Jack asked if the social services department could provide a different bed that had sides, which could be put up. The answer was that the local authority did not supply them. It seemed that people in the past with such beds had still attempted to get out of them and broken limbs had resulted. The local authority was not prepared to be sued in such circumstances and avoided this by not meeting this need. Jill was therefore barricaded in with bookcases and chairs.

The second was continence care. Jill was incontinent and had a catheter inserted. (I was not able to discover whether this followed a discussion about the

pros and cons of the use of a catheter or pads. Jack said that pads would be no good because they would not last through the night.) The district nurse had been changing the catheter at intervals (the interval seemed to vary between the nurses and Jack had no idea what the ideal frequently for changing it was). One day a nurse announced that she could not supply the catheters any more as they did not have the stocks. It was not clear where they had obtained them up until that date but Jack was told to get a prescription from his GP and get the stocks himself. On top of all his caring tasks, Jack had therefore to go to the GP for the prescription and go to a chemist. The large chemist he went to did not keep this kind of catheter in stock and they had to be ordered.

Jill did return to the hospice for brief, respite care visits when Jack found that he needed a break. Jack cared for her lovingly and valiantly at home until she died in the November.

My mother

My mother was a strong, determined person whose primary focus was her family—my father and four children—so she had spent a lifetime managing a large house and garden. My father died before her. In the last few years of her life she began to have little strokes and was less able to do things for herself. She resented her loss of abilities at first but reached the point, a year before she died, when she was unable to do anything for herself. She could not get out of bed or walk unaided and accepted the help that was offered. She could manage to feed herself most of the time and she could talk a little but was not inclined to do so. She sat for many hours doing nothing—with a newspaper in front of her, sometimes the wrong way up! She listened to music but could not seem to follow programmes on the television. I could not see that she had any 'quality of life' yet it was only in the two weeks before her death that she indicated that she was not 'all right'. Until then she accepted her situation and appeared happy with the care she was getting.

My mother, like Jill, was determined that she wanted to be at home. She had the good fortune to have enough savings not to be anxious about money. She had also had the foresight to find a couple to be tenants in a flatlet in her house, the wife of whom was working as a home care assistant for the local authority. For the last 18 months of her life, this couple were employed full-time to look after my mother and the house and garden.

Some assessment must have been carried out at some point because staff from Social Services came

in four times a day to help the full-time carer get my mother up and dressed, toilet her at 12 and 4 pm and put her to bed. My mother was heavy and two people were needed to lift and move her (health and safety regulations required this of paid staff). The full-time carer, because she knew the local networks, achieved a whole range of things for my mother that widened the range of my mother's options. She:

- got my mother up and in a chair every day—except when she was actually ill;
- got a bed with sides because my mother also fell out of bed;
- she got a special aid for the bath and then a hoist so that my mother could have the bath she loved up until almost the day she died;
- got a wheelchair so my mother could sit outside if the weather was nice;
- got a supply of incontinence pads and knew when to use them;
- got various bibs and spoons so that my mother could continue to feed herself;
- made sure that the local hospital looked after my mother properly, when she reluctantly went there for respite care;
- rang the doctor without a qualm when my mother appeared to have had another stroke.

My mother died at home—where she wanted to be—having had what I felt was excellent care.

Observations and comments

There are numerous things that one can draw from these two examples. They may not be typical, although discussions with anyone with a relative needing care in their own home usually reveals some similar experiences. There is sufficient disquiet about current provision to suggest that attention needs to be given to it. Given the expected increase in the number of very elderly people in the population and a policy commitment to more care being provided 'at home', this is not a problem that is going to go away.

I conclude that the quality of care received by many people is not what they want or need. There is clearly considerable variation between areas.

1. In some cases the care that people receive is inadequate. The fact that my mother was dressed and sat in a chair almost every day until the day she died shows that more could have been done to make Jill's life more varied.
2. To call the miscellaneous collection of services Jack and Jill received a 'package of care' would be a joke. Jack, in essence, had to be his own care manager and service deliverer. He had to: plead

to retain the Marie Curie nurse; find and co-ordinate all the care from the private agency; chivvy the GP to write to the hospice for a single room when Jill was there for respite (a number of those with whom Jill was sharing a room initially, died during her stay); collect the prescription and get the catheters; and so on.

3. The social services assessment, if it can be called that, is done at one point in time. But circumstances change quite frequently. In my mother's case her continuing small strokes meant that one day she could feed herself and the next she couldn't. My mother's carer was monitoring the changes as they happened and knew where in the system to go when something different was needed.
4. My mother had an advocate who could make demands on services on her behalf. Jack could not even be encouraged to demand more assistance from the GP but also did not know where to go for help. His was in one of the classic dilemmas for carers. He was anxious not to be seen as demanding because he could not afford to antagonise any of the existing providers.
5. Despite the statutory obligation to consider the needs of the carer, Jack never had his own needs assessed. Yet here was a man whose wife was dying young and who had to comfort two children as well as come to terms with his own loss.

The essential difference, as I saw it, between these two cases was that my mother's care was organised, managed and provided by one, knowledgeable, person—drawing on others as needed. This person was assessing my mother's capacities and needs on a daily basis and also acted as her advocate. Jack and Jill had no such central person co-ordinating services so Jack had to negotiate separately with each one (of many) and he had no previous experience and knowledge on which to draw. He did not know whether the services Jill and he were receiving were the best, or even 'good enough' because he had nothing with which to compare. There appeared to be no assessment of Jill's needs after the first initial visit and no apparent attempt to review the services being provided and whether they were appropriate or adequate.

I concluded that the current care system failed Jack and Jill. It is probably failing many other people who do not have sufficient resources to pay for care privately. The development of Direct Payments to enable people to buy their own care is therefore welcome. But the deep division between a health service, free at the point of delivery, and other services which are means tested means that money alone will not produce an 'integrated' service. Even within the health service cost shunting occurs even though the service is 'free'

(probably the cause of Jack having to get catheters on prescription). Many service users have little information or experience of purchasing social care services. They may need support and assistance to enable them to be informed consumers and to get the most out of having Direct Payment.

Not everyone will want to take responsibility for employing staff directly and it may not be appropriate for terminally ill people, like Jill, to be cared for in this way. But buying services, as Jack did, does not necessarily mean you get good care. In whatever way services are organised there are always going to be a whole range of different people and organisations working to provide services for people with complex care needs. One way to make these services 'person-centred' is to have one person, like my mother's carer, who co-ordinates all other assistance and acts as an advocate.

There are some models of service delivery which have been successfully used in the past and which are now being reconsidered again. In the context of services for disabled children and their families, some authorities have developed key-worker schemes where one person takes responsibility for co-ordinating all the other health, housing and social care services received by a family.¹ There is no reason why this model could not apply equally to other groups of service users.

The service delivery model developed within the Kent, Gateshead and Darlington schemes in the mid-1980s

¹ For example. Suzanne Mukherjee, Bryony Beresford and Patricia Sloper, *Unlocking key working: an analysis and evaluation of key worker services for families with disabled children*. Policy Press, 1999.

related specifically to frail older people. They were all variants of a scheme of a Co-ordinator (or care manager) responsible for maintaining a number of older people in their own homes. The day-to-day care needs of this group were met by part-time care assistants, sometimes working with volunteers, whose work was managed by the Co-ordinator. In the Darlington scheme the care assistants were generic workers trained to deliver a range of simple health tasks as well as social care. The evaluation of the Darlington scheme showed that providing services in this co-ordinated way enabled vulnerable older people to stay at home; that the services were felt to be more reliable, effective and sufficient than other arrangements; that the older people had higher morale; that the distress of carers was reduced; and that the costs were no more expensive than the alternative provision.²

The Joseph Rowntree Foundation currently has a project, which is exploring the possibility of *rediscovering* this more co-ordinated, person-centred approach. In an unpublished paper³ it is concluded that good models of service delivery exist and that further research to identify further models is not needed at this time. What is required is to see whether such models can be put in place within the environment we now have in which services are commissioned and contracted out. Discussions currently in progress may reveal some positive ways forward.

² David Challis, Robin Darton, Lynne Johnson, Malcolm Stone and Karen Traske, *Care management and health care of older people*. Arena, 1995.

³ Janet Lewis and Lucianne Sawyer, *Rediscovering the community care approach*. Unpublished, Joseph Rowntree Foundation, July 2000.