

## **CLIENTS AND PARTNERS: THE ROLE OF FAMILIES IN RELOCATING PEOPLE FROM MENTAL HANDICAP HOSPITALS AND HOSTELS**

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### **INTRODUCTION**

In August 1985 a 58 year old Durham man was found dead in his room in a group home for people with mental handicap. A post mortem found that he had died from epilepsy. Ten months earlier he had been moved out of a local authority hostel where he had been living since his mother died in 1977.

The case was referred to the local ombudsman by the man's brother who complained that it had been wrong to move him because he was not capable of looking after himself. The brother was also aggrieved because he had not been consulted.

The commissioner concluded that no blame could be attached to the council for the man's death; that the officers concerned had acted responsibly in the decisions they had taken; and that there was no reason to question the quality of the support given.

She did conclude, however, that the council should have told his brother of the move and given him greater opportunity for contact. "I see this failure as mal-administration", she declared. The Director of Social Services accepted the commissioner's strictures as fair. "We are reviewing existing practices", he said, "to ensure that a breakdown in communication like this does not happen again" (Community Care, 1987).

The ramifications of this judgement go well beyond the particulars of the case. The commissioner's finding has a bearing on social services departments and social work practice up and down the country. Crucially it concerns the role (and rights) of families and relatives in the process of relocating people from one type of accommodation to another; usually from long-stay mental handicap hospitals into community-based units or from hostels into independent living schemes.

The drive towards community care initiated by national policy and the closure or run-down of mental handicap hospitals has given new force to this issue. The numbers of people moving are rising steadily year on year. Agencies and workers cannot proceed on the basis of drift and get-by, as the Durham case demonstrates. What part families should play in relocation decisions and in the process of moving is a question of policy and practice that must be confronted seriously and not fudged. Ultimately the answer may affect how well individuals adjust to any move and the outcome of the new placement.

### **THE KIRKLEES RELOCATION PROJECT**

The aim of this paper is to explore some of the reasons why it is important to involve parents or other relatives in all stages of the relocation process, and to

highlight some of the dangers of not doing so, using evidence from our own research evaluation of a community care programme in one local authority area.

The Kirklees Relocation Project was set up with funding from the Joseph Rowntree Memorial Trust to assess the impact of moving out of mental handicap hospital and hostels on the movers themselves and their families. The research design comprises three stages. We are talking with staff, relatives and the residents themselves before the move, during the settling-in period and one year later to see what changes, if any, occur in the well-being and lifestyles of our subjects. The first two phases of data collection have now been completed. Currently we are involved in the interviewing for the twelve-month follow-up. This paper draws on information from the first two phases of our fieldwork.

Our cohort of movers includes 21 people who have left a long-stay mental handicap hospital to live in local authority hostels and 24 people who have been transferred from hostel accommodation into houses and staffed flats, family placement schemes or other independent living units. Altogether, 37 of these people (18 hospital movers and 19 hostel movers) still have close, living relatives or surrogates. In nine cases the relatives declined to talk with us when approached or could not be contacted. At least one relative and usually more of all the remaining 28 movers was interviewed. In total 44 relatives have participated in the two initial phases of the study. In addition, there were three hospital residents originally included in the relocation programme who, for one reason or another, did not make the move. All three had relatives whom we interviewed. This article uses material from the interviews with these relatives to highlight some issues concerning their involvement in placement decisions and the process of relocation.

### THE RELOCATION PROCESS

From our lengthy interviews with relatives it became clear that the majority were alerted to the changes afoot long before anything definite happened to involve them personally. The policy of moving people out into the community was being talked about on television, featured in local and national newspapers and rumoured at the hospital. Over half the people we interviewed said that this had been a worrying time for them:

'I began to take an interest in programmes about it and there were some awful tales of people being left to wander the streets.'

'It was upsetting – wondering where they would be going, whether they'd like it and whether they'd settle.'

'I was bothered they might move her further away.'

This phase – when plans are in the air but before they have taken shape – is always a difficult one to handle for all concerned. Officials may feel the need to tread warily through the myriad of interests involved aware that a false step might lead to all kinds of trouble – from staff unrest and union problems to neighbourhood opposition, inter-agency conflict and the closing of options by political gamesmanship. Perhaps not surprisingly their instincts might be to keep things under wraps until the details have been sorted out before going public.

For relatives, on the other hand, the uncertainty induced by such secretiveness is likely only to breed insecurity and anxiety. The inevitability of leaks and the efficiency of the rumour-machine ensure the word will soon get around that changes are in the pipeline. Misinformation, half-truths and guesswork will quickly fill the vacuum. The real danger is that concerned relatives will align themselves on the

basis of their inadequate knowledge in anticipation of a worst-case scenario. In the short term such a stance may produce needless stress and worry and foster a lack of trust in the professionals making the decisions. In the longer term, as we shall show, such attitudes can influence how successfully the new placement works out.

Probably there is no way of avoiding completely these problems. At this early stage in the relocation process the concerns of officials and relatives inevitably seem to pull in different directions. Nevertheless, there is a strong case for proceeding in a manner that is likely to minimise worry and misunderstandings. The essential ingredients of such an approach are active consultation; direct, personal contact and *straight-dealing*. This calls for a deliberate and well thought-out policy on the involvement of relatives with procedures to match.

The evidence from our study suggests that such an agenda was lacking. Instead things were handled in a piecemeal and haphazard way case-by-case. Accordingly, families' reports varied widely as did their feelings about the experience.

Some families were formally informed many months before the move was scheduled to take place; others received no formal notification of any kind. Of those we interviewed (excluding two cases with insufficient data), ten recall having had a letter informing them of the impending move and most of these then received a follow-up visit to discuss the proposed new placement; a further three families also reported being visited at home. Six were told over the telephone by a hospital consultant, a social worker or a member of staff at the hostel where the relative was then living. Two found out from staff on one of their regular, weekly visits.

At the same time, fully eight of our families (five involving parents) said they heard first hand about the transfer from their son, daughter or relative (in a few instances only after they had actually moved). While most of these families were contacted later by the agencies or pursued the matter themselves, three profess to having no official word at all about the move. Indeed, in two cases our contacting them was their first intimation of what was happening. All the eight cases in this last group involved people who were moving out of hostel accommodation into ordinary housing or independent living schemes.

Indeed, closer analysis of the data points to a marked difference between the involvement of relatives in the process of moving people out of hospital as against moving people out of hostels. When we asked families if they felt they had been consulted about the move (in the sense of having their views listened to or taken into account) over half answered they did not. This crude total, however, masks a more significant finding. Families whose relatives had moved out of hostels were disproportionately represented among those who were dissatisfied.

Twice the number of hostel relatives as hospital relatives voiced such concerns and altogether two-thirds of them expressed some criticisms either about being sidelined or about feeling their opinions did not matter.

'They listened but I don't think they took much notice. The staff said they would be having more meetings to discuss the move but if they have them we haven't been invited.'

'I think they had already made an assessment and the decision was cut and dried.'

Some of the hospital relatives similarly met with attempts to bounce them into going along meekly with professional decisions – sometimes of a heavy-handed kind:

'... (We were told) that if we didn't agree to Sandra moving to a

hostel then we could take her home for good and they would refuse to take her back.'

For the most part, however, there were fewer complaints. Two-thirds of the hospital families said they were happy with how they had been consulted.

'I think they've been very thorough. They've had meetings where I could ask anything and they've answered everything to my satisfaction.'

### THE UNDERVALUATION OF FAMILIES

The reason why these two groups reported such different experiences calls for explanation. The easy answer is that more effort was put into consulting the relatives of people moving out of hospital because the process was seen as more problematic from an agency perspective. From the perspective of the families themselves, however, the hostel relatives were if anything more concerned about the risks of transfer because of their fears about the loss of supervision and support in more independent types of living accommodation. This interpretation suggests that the feelings of dissatisfaction voiced by the relatives of hostel movers arose from an undervaluing of their needs for information and reassurance on the part of professionals.

*Our close dealings with the relocation team over the past two years have led us to the view that such an explanation presents an undeservedly negative and over simple picture. Although correct in its details it nevertheless casts events in a misleading light. The hostel relatives were given less attention usually not because of some omission but as a consequence of social workers seeking to apply what they saw as principles of good practice.*

These principles of good practice were grounded on two basic assumptions: that the hostel movers are adults and should be treated as such; and that in each case the individual mover should be regarded as the client. The upshot of this line of thinking was to exclude the families from the process of decision-making and leave it up to the movers themselves to keep them informed of what was going on. Our research shows that this approach, although well-intentioned, is also misguided.

Two case studies from our files illustrate the dangers:

- ★ Gary Smart is in his late 30s; a founding member of the local People First group. For a long time he had wanted to move out of the local authority hostel where he had lived for a number of years and into a place of his own. He knew he could cope and the hostel staff shared his confidence. When the opportunity of moving into a single flat came up he grabbed at the chance. Any reservations that his parents might have had if their opinions had been sought would not have influenced his decision. It was something he wanted to do for himself and rightly so.

It was some weeks after he had moved into his new flat before his parents found out where he was living. Social services staff had left Gary to tell them himself and he had not done so. The Smarts were angry and deeply upset at being left in the dark. The relationship between Gary and his parents is close but volatile at the best of times; this episode almost caused a permanent rift. When Gary had been living at the hostel he would walk up to his parents' home often twice a week but following his move he only visited once in two months.

His parents harboured genuine worries about him. Gary had a history of epilepsy and some violence and the idea of him living alone with minimal supervision caused them real anxiety. Yet they felt they had been excluded altogether from the process of the move. They did not understand how it was now possible for him to cope on his own when in the past they had been led to believe he would always need daily

supervision and care. They were also fearful of what might happen to him if things did not work out and where he would live then.

These frustrations spilled over into the Smarts' relations with social services staff where their attitudes had already been coloured by previous disagreements – most recently over the wisdom of allowing Gary to take his cycling proficiency test despite his poor balance, lack of road sense and the possibility of fits.

For a while, communications between Gary and his parents broke down. For Gary especially this rift was an added strain on top of the pressures of settling into his new home and adapting to his new way of life. The strain brought problems in its wake. He became incontinent, left his bed unchanged for months and stored piles of newspapers in his bedroom.

Over time the relationship between Gary and his parents got back onto an even keel and he again visits them on a weekly basis. He is now managing quite adequately in his flat. The Smarts however remain bitter about their lack of involvement and have rejected subsequent attempts by social services to repair the breach.

★ Janet Pringle, in her early 40s, had lived with her parents all her life. When her mother died, she and her father, by then in his 70s, managed the house together and Janet had a job during the day.

Last year her father fell seriously ill and was rushed into hospital where he made a slow recovery over a period of four months. Meanwhile Janet was taken into the local hostel and there she found a new freedom and met new friends. When the possibility of moving into a staffed house with some of her friends was offered to her she decided to go and settled easily and happily.

Back on his feet again, though frailer and prone to lapses of concentration, Mr. Pringle had to learn to live on his own. When we interviewed him about Janet's move he told us she was nothing to do with him anymore and was very reluctant to talk about her. He knew very little about her circumstances and understood only that she didn't want to return to him. There was no bitterness in his feelings, only hurt, especially about her not visiting him since leaving the family home a year ago.

The second time we called to see him there had been a sea-change. Janet had visited recently and had taken two of her new friends with her. Mr. Pringle had been thrilled and eagerly told us how well she had looked with a new hairstyle and bright, fashionable clothes. It looked as though their unhappy estrangement, which only ever came about for want of a go-between, was over.

#### WHY INVOLVE FAMILIES?

These two vignettes show how the failure to ensure that relatives are involved in relocation decisions can bring about a whole series of problems over and above those stemming from the pressures of moving. Broadly speaking, these problems fall into three main categories:

- (a) Feelings of exclusion, rejection, anxiety, anger and fear on the part of parents and families. As one of our parents said, 'It's the lack of recognition of us that hurts'. Such feelings may simply fester in the lives of these families or foment their opposition to the new placement. Either way they can seep through and affect the trauma of moving for the individual and how well he or she adjusts to the change in environment.
- (b) Breakdowns in the relationship between families and professionals. When this happens the individual caught in the middle can be seriously disadvantaged from having no-one outside the system, but with a stake in it, to represent their interests or speak up for them.
- (c) Upsets or severance in the relationship between parents and their (now adult)

children or between the wider family and their relative. For people whose family ties often represent the only stable and continuous, close, personal relationships they have, or might ever have, in their lives such an outcome can often offset any conceivable gains accruing from their new life-style.

There are positive reasons also for involving families over and above the fact that the risks of not doing so are too great.

Research suggests that family involvement in the relocation process and family approval of the placement are critical factors in successful community integration (Schalock et al, 1981). Indeed, the quality of the community support system has been identified as more important to the success of community living schemes than the characteristics of the people who move into them (Heal et al, 1978). The family is often the key source of such support.

The family too can help to ease or prevent what is often called 'transition shock'. This refers to a range of adjustment problems and stress reactions frequently encountered by individuals facing major changes in their pattern of living following relocation (Macy, 1984). The most common symptoms are emotional, behavioural and mental health changes including changes in adaptive functioning. The disruption of familiar social relationships is just one of the triggers that seem to produce an adverse effect on personal adjustment. While the degree to which residents are psychologically prepared for the transfer can have a bearing on how well they cope with the challenge (Heller, 1984).

In this context, families offer stability and continuity; they are a fixed point of reference for movers when all else around them is in a state of flux. They can provide the emotional security needed to fill the void before new friendships are formed and before new bonds of trust and affection are built up with other residents and staff in the new setting. Moreover, knowing that their families support the move and being able to talk it over with them can help individuals into the right frame of mind.

The reasons for family opposition to community placement are rarely selfish or deliberately obstructive. Usually they are expressions of love and concern (Fairbrother, 1983). Parents may feel their son or daughter is being pushed into a situation for which they are not ready. The family may have fears about harassment, intimidation or exploitation. Such qualms can almost always be lessened or allayed when they are addressed directly and when families are drawn into the relocation process early enough for them to feel their views have been taken into account.

This cannot be done where the job of informing their family is left to the movers themselves. By then the crucial decisions have all been made and the opportunities shut off for meaningful family involvement. The kind of worries mentioned above have no outlet and in many cases the chances of teaming up with the family to smooth the passage into the new placement will have been lost.

## **RELOCATION AND FAMILY STRESS**

There are other, equally powerful arguments against professionals treating the individual mover as the client to the exclusion of the family in relocation decisions. While the thinking behind this approach may seem to accord with the principles of normalisation it actually masks bad practice by staff.

Leaving the people who are moving to pass on the news to their families conveys three coded messages: that the decision has nothing to do with them; that their opinions don't matter; and that staff know best. It also puts the movers in an

impossible position: having to cope with questions they can't answer or feeling they have upset their parents or facing the brunt of their family's opposition.

There is a host of questions that parents might reasonably be expected to ask about any transfer. Will their son or daughter be able to manage 'in the community'? Who are the other residents? What will they have to do for themselves? How much staff supervision and support will be available? Will it affect current day care arrangements? What will happen if the placement doesn't work out? What extra responsibilities, if any, does community care place on the family? The movers themselves cannot be expected to answer these questions and the deference shown by so many families to professionals will inhibit them from pursuing the matter. The onus must be on staff to take the initiative in communicating with families and in creating the opportunities for them to have their say. Equally, the movers cannot be expected to cope with the emotional loading their relocation in the community might hold for their families. Indeed, relocation should be seen as a potential crisis for families. Many will have built up a rationale for why their relative needs a sheltered and protective environment which comes crashing down on his or her moving out (Crine, 1986). Some may not believe their relative can possibly manage in a home of his own when before they had been told the only realistic prognosis was a life-time of dependency. Avis (1978) captures the conundrum for many parents caught between wonderment and confusion that:

'their now-adult child, duly labelled as in need of life-time protection and lacking in judgement, was now granted the status to make such important decisions. The person who was now an adult was viewed as capable of making choices when the family had been assured that theirs was an eternal child.'

Stedman (1977) similarly points out how relocation is often a cause of stress for

Families need help to cope with these emotions and to work them through and painful revisitation of earlier decisions to let their child go which often occurs at this time. In the process old wounds may reopen. Parents in particular might again begin to question whether they did the right thing. Long suppressed feelings of guilt about rejecting their child might be reawakened. Some may experience anger about what they now see as wrongful advice they were given in the past.

Families need help to cope with these emotions and work them through and the surest way of doing so is by involving them in all stages of the relocation process. Families may also need help in coming to terms with their relative's new status and identity. As our two case studies show, trouble and strife can arise when families fail to understand how their relative's greater independence and new way of life might reshape their routines and the relationship between them. An episode involving the Smarts is worth reporting.

★ Gary Smart usually calls in to see his parents once or often twice a week. After one of his visits he did not show up again for over a week and his father decided to ring the hostel where he used to live before moving into his own flat to see if he was all right. The Smarts allege they were informed that Gary had been told not to visit them, and if they wanted to know how he was they should go and see for themselves. (Mr. Smart the elder is almost blind and partly paralysed from a stroke.)

Some days later Gary rolled up again at his parents' house only to be told by his father to go away because the hostel staff had instructed him not to visit. Gary was dumbfounded by his father's behaviour. When his mother put him in the picture, Gary explained that he hadn't visited in the past two weeks because he'd had a cold and didn't want to infect his dad. He then became very angry too and told his parents

that he'd 'give a piece of my mind to that lot at (the hostel). They aren't going to tell me when I can visit my dad'.

Subsequent enquiries at the hostel revealed a different story. The Smarts had indeed rung up but, according to the member of staff who'd talked with them, he'd merely said that hostel staff were not in a position to tell Gary when he should visit them; that it was up to him to decide.

This little drama arose mainly because the Smarts had not grasped that their son was now much more his own agent, that the role of hostel staff had changed accordingly and that, as parents, their expectations too would have to change. Many families - like the Smarts - need themselves to be carefully prepared for the move and to have its implications for them pointed out sensitively.

### A STRATEGY FOR INVOLVING FAMILIES

Three main arguments have been put forward for ensuring that families are fully involved from an early stage in the relocation process:

- (a) because failure to do so can cause problems for the person who is moving;
- (b) because families can ease the transition for the movers and assist them in the process of adjustment to their new life;
- (c) because relocation often places families themselves under stress.

These points bring to the fore an issue running throughout this discussion: an issue that has long absorbed social workers in many fields of practice. It is perhaps best summed up in the often repeated question, 'Who is the client?'

In the case of the hostel movers in our study the agency response was unequivocal: the individual mover is the client. We have set out to show that this approach is too narrowly circumscribed and should be widened to take in the families:

- (a) as **clients** where they need advice and support concerning the reasons for the move, how it might affect them and any worries they may have; and
- (b) as **partners** where they can help in preparing their relative for the move and in settling-in afterwards.

The ambiguity of this dual role as clients and partners is more apparent than real. For in fact both roles require essentially the same struts: easy access to the professionals managing the move, involvement in the preparation of individual programme plans and a say in the outcome of case decisions. How might such involvement be ensured?

Our own study of families and evidence from the wider research literature (Braddock and Heller, 1984; Atkinson and Ward, 1987) suggest a number of practical steps or principles:

★ *'Before hospitals are shut down they should consult everyone involved rather than just being told.'*

*'Gary told us three or four years ago that some other people were moving. We never heard anything about Gary before he moved.'*

The families of likely candidates should be informed in writing of the general plans for relocation, their rationale, the stage reached and the proposed timetable for their relocation, their rationale, the stage reached and the proposed timetable.

★ *'They've taken her over now, and we haven't really had any say but I think we should have been asked. We would have liked to know before the decision was made.'*

They should be given an assurance that no decision about the placement will be made without full consultation with them.

- ★ *I think parents should be informed more. I sit here worrying and worrying on my own.*  
They should be given the name and telephone number of a contact officer in the Relocation Team who thereafter will act as their personal link with the agency.
- ★ *'After initial contact another year elapsed before I heard anything again. In fact I had to ring (the social worker). They should keep parents informed more.'*  
A home visit should be arranged within a fortnight of first contacting the family.
- ★ *'I would have suggested that I would have liked Robin to have been in some sort of sheltered housing so that if anything happened he could just press a button.'*  
The types of placement available and considered suitable should be explained to the family and any options they might put forward should be welcomed.
- ★ *'There should be more involvement and discussion in a group of those affected by the move.'*  
Families should be offered the chance of visiting placements similar to those being considered for their relative and, if appropriate, the opportunity of talking with others whose relative has made a similar move.
- ★ *'I think they could let us know sooner and perhaps have regular meetings to discuss how things are going.'*  
*'I would like to have been involved more while she was being discussed.'*  
Families should be invited to all programme planning meetings concerning the placement of their relative which should be arranged to facilitate their attendance.
- ★ *'I think we should have been listened to before the decision was made.'*  
While parents or families should not have a veto over the new placement no decision should be made about relocation without them being given the opportunity to participate. Although conflicts of interest might be expected occasionally, and parents' wishes may sometimes differ from those of their son or daughter, this cannot justify ignoring the parents' views (Conroy, 1985). When decisions have to be taken without their approval the onus is on those concerned to ensure that not taking such a step would do more harm than will be done by flouting the parents' wishes (Fairbrother, 1983).
- ★ *'Nobody has really let me know that she's moved. In fact on the 4th July I rang to say I wouldn't be coming to see Amy because I would be going to a wedding (and) then they told me she wasn't there. They hadn't let me know.'*  
Irrespective of whether they attended the placement meeting, families should be formally notified by letter of the move and when it is to take place without delay.
- ★ *'I think they should have let us know; let us look around his new flat.'*  
Families should be encouraged and helped to visit the new placement before the move, to meet the staff (if any) who will be working there and any other residents – where possible with their relative.
- ★ *'There was a meeting at (the hostel) and it was then that they told me. There was going to be another meeting but it never happened. I had a letter to say they were moving on the Thursday and Deidre rang me on the Wednesday to say they were in.'*  
Families should be enabled to attend the actual transfer if they and their relative wish.
- ★ *'There should be more contact at every stage with parents. They want to know what's happening to their children.'*  
Where appropriate during the settling-in period, arrangements should be made for families with transport problems to visit their relative and vice versa.
- ★ *'I think they ought to keep in touch with relatives. We want to show our appreciation.'*  
A home visit should be arranged by the family's contact officer within six weeks after the move to discuss any problems, anxieties or queries.
- ★ *'I rang to speak to the Officer-in-Charge (at the hostel) about the plans and there was a case conference regarding Guy's move – but they wouldn't have included me if I hadn't phoned.'*  
A full review should be held in each case not more than three months after the move to which the family should be invited. Where no-one can attend, a home visit should be arranged by the contact officer to report on and explain the outcome.

Even following these steps it is unlikely that all friction between professionals and families will be avoided or that the fundamental asymmetry in their relationship (Gliedman and Roth, 1981) can be corrected and overcome. Families who have learned over the years to live with the barriers erected against them by institutional practices, may take a while to gain confidence in a more open, sharing type of approach. At some time in the past most will have been let down, misinformed or excluded. Such experiences may understandably lead them to take a very sceptical view of agency intentions, the promises of professionals, or their readiness to deliver. The practical steps outlined above may not go all the way towards surmounting the backlog of poor communications but at least they would show a measure of good faith.

### SUMMARY

This paper examines the involvement of families in the process of moving people from mental handicap hospitals and hostels into the community. Drawing on evidence from the Kirklees Relocation Project, the authors show that families are often excluded from important decisions and not informed of their outcome. This can lead to problems in relations between families and professionals, and families and their relatives, as well as possibly making it harder for movers to adjust to their new way of life.

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