

Quality of Life Following Resettlement for Three Elderly Men

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Introduction

Recent research into resettlement from long stay hospitals¹ concentrates on limited aspects of quality of life, ignoring essential aspects such as choice, and personal relationships. The methodology used is sometimes limited in what it shows, and the majority of studies concentrate on the younger person with learning disabilities.

In the North West emphasis has always been placed on the outcome of resettlement for people themselves in terms of a wide ranging view of their increased opportunities and experiences. The only way to approach this kind of understanding is to look in detail at how particular people's lives have altered. This study aimed to describe three elderly men's experience of resettlement from long stay hospitals to a metropolitan district in the North West.

Because so little attention has been paid to the outcomes to be achieved by elderly people through resettlement, the study included some comparison of the lives of the elderly men with learning disabilities with an active elderly man who has no learning disabilities.

General Aims

The general aims of the study were as follows:

- To describe the quality of life for the three men as it is now.
- To assess the extent to which their quality of life has improved since being resettled, by comparing it with what their quality of life might have been like whilst in the long stay hospitals.
- To assess how their quality of life compares with that of an active elderly man of similar age who does not have learning disabilities.
- To evaluate how successful resettlement has been for the three men, in terms of improvements in their quality of life, opportunities and experiences.

¹ See for example, work listed in Reference section and Appendix 2.

Participants²

Summary of Biographical Details of Men With Learning Difficulties: Jim, Fred and Brian

Brian, Jim and Fred³ have severe learning disabilities, and are in their late 60's and early 70's. They have all lived in long stay hospitals for the best parts of their lives.

Brian and Jim were chosen to live together because they had spent most of their lives together, and it was thought they were compatible. Fred was also thought to be compatible for living with Brian and Jim.

The men began their resettled lives during February 1990, and at the time of study had been living in the community for a period of 8 months.

Summary of Biographical Details for an Elderly Man Without Learning Difficulties: Harry

Harry is 79 years old. He does not have learning disabilities. Before retirement he was a railway worker. He lives in a one bedroomed house in a residential neighbourhood where he has lived for about 7 years. The property is owned by the council.

Information Gathering

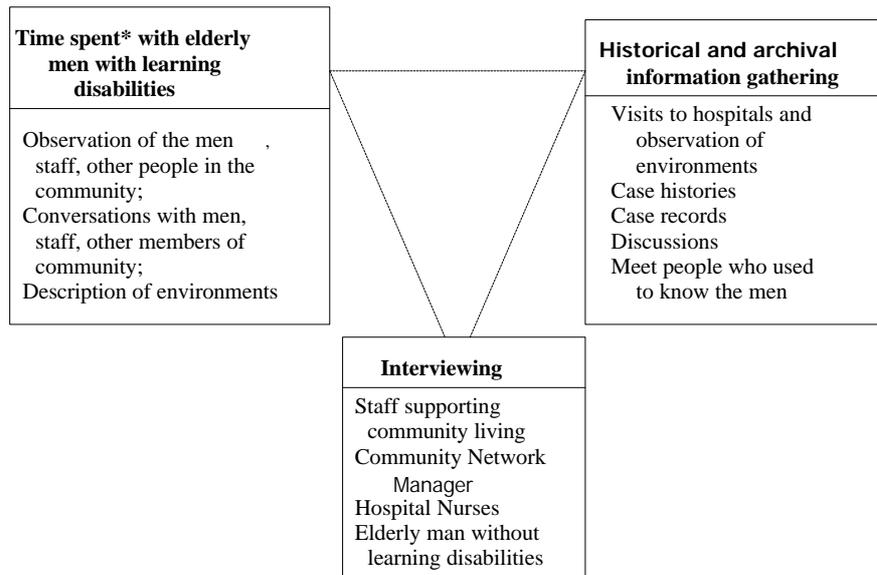
Qualitative information was gathered relating to:

- life in long stay hospitals for the elderly men with learning disabilities;
- life in the community following resettlement;
- life for an active elderly man in the community without learning disabilities.

Different sources of information were triangulated in order to get as full a picture of the men's quality of life as possible. Sources are shown in Figure 1.

² Many thanks to the men, their staff and the service managers who participated in the study.

³ Not their real names.



*Researcher worked as a staff member across all shifts in group home for elderly men with learning disabilities for one week

Figure 1
Sources of Information Gathered

The information was collected from October - December 1990. Thus a 'snapshot' of the men's lives was taken, in the context of continual change and development. This 'snapshot' is unable to capture the *process* of supporting people in community living. Every day's experiences lead both staff and residents to do things differently in the future. All this 'snapshot' can do, is describe what life was like at that point in time and how it compared with hospital life and that of an active elderly man without learning disabilities. Ongoing reviews and observations are required to describe the process of community living and increasing quality of life.

Where Are Brian, Jim and Fred Now Living?

The living environments have changed considerably for Jim, Fred and Brian and they are now more similar to Harry's home (the elderly man without learning disabilities), than the hospital. Table 1 summarises the features of their homes prior to and following resettlement.

| Lifestyle | Type of Accommodation | Location | Neighbourhood | Local Facilities |
|---|---|---|--|--|
| 3 men with learning difficulties in hospital (Jim, Fred and Brian) | B & J-42 bedded ward long stay hospital. Lived in large bedded wards. 6 mths prior to resettlement lived in bungalow in hospital. | In countryside about 1-2 miles from nearest village/small town. Long driveway up to hospital. | Wards have different names. Hospital mainly only residential accommodation in area. Other types of residential dwellings a distance away. Males and females segregated in wards. | No local facilities as hospital in its own grounds in hospital. Hairdressers, social club, cheap lager, an adult training centre, cinema at nearby hospital, bathing facilities separate from wards. |
| 3 men with learning difficulties in community (Jim, Fred and Brian) | Rented house from housing association. Semi detached front and back garden. | In neighbourhood approx 3 miles from city centre, about 5 minutes walk from nearest shops. Looks out onto small block of flats. | Street of similar houses. Occupied by a mixture of young, middle aged and older people. Working class area. | Local church at bottom of street. Local newsagents, post office, banks, pictures, pub, chip shop. Supermarket about 15 minute walk away. |
| Elderly man with no learning difficulties in community (Harry) | Rented council house. Terraced, small back yard. | About 1 mile from town centre, backs onto a railway line. Green centred in middle of surrounding houses. | Area mainly occupied by elderly, middle aged, working class area. Small units for elderly people situated in street opposite. | Social club and local pub around corner, also off licence. Nearest post office and shops about 10 minutes walk away. |
| | Internal Accommodation | Facilities | Furnishings | Personalisation |
| 3 men with learning difficulties in hospital (Jim, Fred and Brian) | Ward where Brian used to live now sectioned into bedrooms of about 5 people. All wards have lounging areas with TV, kitchen, although main meals not made here. | Bedrooms small, kettle, TV. | Small storage space in bedrooms, dining table, comfy chairs. | Couple of pictures on walls. |
| 3 men with learning difficulties in community (Jim, Fred and Brian) | 3 bedrooms, Fred and Jim share one room, bathroom, toilets separate. Kitchen, lounge, dining room. | Two TV's, one video, telephone, kettle, cooker, central heating. | One sofa, dining table and chairs, two settee chairs, dining room cabinet, cooker, own wardrobe, chest of drawers, washing machine, tumble dryer, net curtains, mainly modern furniture. | Pictures in Brian's room. All different bed spreads etc. Ornaments in dining room, pictures on wall. |
| Elderly man with no learning difficulties in community (Harry) | One bedroom, one bathroom, separate toilet, lounge, kitchen. | Kettle, coal fire, gas fire upstairs, cooker, television. | Sofa, one comfy chair, cooker, bedroom furniture, ie. wardrobe, mirror, bedside cabinet (mainly old style furniture). | Pictures of family on walls of bedroom and lounge. Cushions on settee and other pictures and ornaments. |

Table 1
Main features of homes prior to and following resettlement

What Is It like for Brian, Jim and Fred in the Community?

The approach to quality assessment promulgated throughout the Region adopts the five service accomplishments, suggested by O'Brien and Lyle as a framework for exploring the outcomes (in terms of the experiences of people with learning disabilities) of services (Burton 1992). The five accomplishments can be summarised as:

- Presence in the Community
- Respect
- Power (Control and Choice)
- Capability
- Participation

Appendix 1 outlines each of the accomplishments.

Each accomplishment will be taken in turn and changes in quality of life for Jim, Fred and Brian assessed in relation to their lives prior to resettlement and in comparison with Harry's quality of life.

Presence in the Community

Means sharing places and activities with ordinary members of society.

The Three Men in the Community

In general it was observed that the men's community life was organised around a variety of community places, although it was striking that they did not go out very often.

Table 2 outlines the occurrence of different community activities throughout the week.

| Person | Activity | Occurrence | Day |
|--------|--|------------|------------------|
| Brian | Walking to post office | 2 | Monday/Tuesday |
| | Walking to shop (newsagents) | 2 | Wednesday/Friday |
| | Walking to pub | 1 | Monday |
| | Taken by car swimming | 1 | Wednesday |
| | Going to cookery class | 1 | Thursday |
| Jim | Walking to shop (newsagents) | 2 | Wednesday/Friday |
| | Walking to pub | 1 | Monday |
| | Driven to supermarket | 1 | Tuesday |
| | Walking to pictures | 1 | Thursday |
| | Walking to takeaway | 1 | Friday |
| Fred | Walking to church | 1 | Sunday |
| | Walking to bank | 1 | Monday |
| | Walking to post office | 1 | Monday |
| | Walking to shop (newsagents) | 1 | Friday |
| | Driven to supermarket | 1 | Tuesday |
| | Catching bus to town shopping | 1 | Wednesday |
| | Shops used: shoe shop department store eating out picture shop | | |
| | Walk to barbers | 1 | Tuesday |
| | Walking to Adult Education Centre | 1 | Thursday |
| | | | |
| | | | |
| | | | |
| | | | |

Table 2
Activities in the community and their occurrence throughout the week

(Observations were made whilst working shifts throughout the week. Therefore, approximately one third of one week was observed).

Jim and Brian do not go out as much as Fred, which is ironic, especially as one of the care assistants said:

"Brian and Jim find the house too small, and the area restrictive because they haven't the freedom to roam around that they had in hospital".

However, presence in the community is not easily established.

A care assistant suggested that:

'presence in the community' is the hardest thing to happen as some people build up bad relations because of their behaviour".

Despite the difficulties, all three men do now appear to have been accepted by their local community, and from observations it appears they are known in the post office and local shops by most people. It helps that people are friendly. One care assistant put it thus:

"The fellas are lucky in that there's a lot of community spirit around the whole neighbourhood".

Presence in Community Within Long Stay Hospital

In hospital, limited use was made of the local community. As the network manager, an ex-hospital nurse, put it:

"All their leisure things were on site ..." and "there was something going on 7 nights a week ... so they'd have a very hectic social life. They would go out on a regular basis from the ward in small groups to Blackburn ... So they wouldn't actually have missed out on anything, but it was very sheltered".

Most leisure activities took place within the hospital itself.

Even so, entering into the community did not occur on even a daily/weekly basis for many of the residents within the long stay hospitals.

Presence in the Community for Men With No Learning Difficulties

Harry, however, led a far more active life. As he said:

"I also walk to town most afternoons, where I get my bits and bobs of food".

He has regular use of public transport and frequently undertakes social activity.

"I go to the neighbouring town once a week every Saturday. I catch the 12.00 train and go to the railway club".

"About 3 or 4 nights a week I go to the social club just down the road".

Whilst Harry's week is busy, there is little variation week by week and he normally follows a regular weekly routine.

Respect

Means being seen as, and treated as a worthwhile and valuable member of the community.

The Three Men in the Community

Various aspects of the men's lives contributed to enhancement of either positive or negative aspects of their identities. Table 3 outlines those events contributing to either positive or negative identities via the respect shown to the men.

| | Events which contribute to positive identity | Events which contribute to negative identity |
|----------------|---|--|
| Brian | Opening front door (the house is theirs) Handling money with some help Being told when things are going well or going badly by staff Being greeted by people in the street Walking into the cookery class first Acknowledging he talks about Blackpool Ordering a drink at the canteen Proving he can do things for himself | Walks on people's heels (told to stop it) Made to sit close to table when eating, so food doesn't fall everywhere Poking Jim and getting hit by Jim for doing this (little respect for each other) Staff talking about him in front of him |
| Jim | Answering the front door Being able to have money when it's needed Signing bills Realising he gets upset easily so trying to prevent this e.g. when buying clothes Apologising when he's been wrong i.e. hitting Brian, being in a mood Being left alone when he's in a mood Trying to understand what is being said when he talks Care assistant lets Jim know when she's annoyed with him Watching out for safety - like crossing roads | Not being listened to all the time when talking Thumping Brian when Brian annoys him Being shouted at by staff when he's in a mood Being uncooperative saying he won't do things because it's the staff's job |
| Fred | Being told what is happening to his money Being asked what he wants for his room Asking in the shop for a brand of cigarette Paying for his own fare on the bus Being told that he will be able to buy a chair when the money comes through Showing he is pleased with what he has bought | Letting himself get wet in rain Not doing things like putting his hood up until someone asks him if he wants to Shop assistants not realising he can think for himself, talking in a loud voice, calling him 'son' Treated differently when buying lunch Public comments such as: "Isn't it nice of both of you to be taking him out" |
| General | Men made to answer door/telephone (it is their house) Being consulted about things that effect them Being left to themselves when they want to be Doing what they want in their house Being encouraged to do things for themselves | Staff sometimes talk about the men in front of them Being shouted at by staff sometimes |

Table 3
Observed events that reflect positive and negative respect and thus identity

(Observations were made whilst working shifts throughout the week. Therefore approximately one third of one week was observed).

The men appear to be treated as worthwhile members of the community by locals. One of the care assistants pointed out that:

"Most people will stop and say hello, particularly now that the men are known more in the area".

However outside the local community where the men are not known the attitude appears to be different. Whilst shopping for shoes for Fred, it was noticed that he was treated as a person with a problem. A shop assistant commented to the staff: "Are you his social workers?", and talked to him in a loud voice as if he was deaf. A woman said "Isn't it nice of you both to be taking him out". These comments emphasised that people saw Fred as different to them. The staff saw this kind of difficulty as transitional.

"Hopefully, as more people are resettled and society becomes more accepting to people with learning difficulties it should become easier".

In observing and discussing respect and dignity it would appear that the men often do not have respect for each other. It was observed and also commented upon by one of the care assistants that Brian will annoy Jim by poking him and so Jim will punch Brian back. They are sometimes separated because of this during the day, although they have to share a bedroom.

During the week, whilst in the house the men do not interact with each other much, and staff do little to encourage them to do so.

However, interaction between staff and residents is quite high as staff are often trying to get the men to undertake activities.

Staff views about community living are linked to respect. Surprisingly, some of the staff felt it was wrong to resettle such elderly men. One care assistant suggested it was cruel to have taken Brian and Jim out of hospital:

"Why at 71 should they suddenly have to start doing things for themselves and be expected to do it?".

However, another staff member thought that respect and dignity can be achieved through ordinary living.

"Because they've got learning difficulties doesn't mean they're not entitled to life as anyone else, being happy, sad, doing boring everyday tasks, and rights to self respect, and to say I'm an individual person".

Having a variety of experiences, alongside other respected and valued people, is an essential step to being treated as a worthwhile individual.

It would seem that respect and dignity feature largely in the men's lives. They are not always treated with positive respect and accorded positive dignity. Although some of the ways they benefit would appear very minor to people without learning disabilities, they are, nevertheless, of great importance to Brian, Jim and Fred, given their impoverished experiences.

Respect Shown in Long Stay Hospitals

The men whilst in hospital, would have had little chance to have been seen as valued members of the community, as they were kept segregated from the towns and villages except for occasional visits.

The men were also treated with violence at the hospital. Although this is unlikely to be the case now, Jim still remembers events of 30 years ago which he still talks about.

The whole hospital atmosphere does not conjure up any feelings of respect and dignity. A number of staff commented that Brian and Jim were able to wander round the whole day without anything to do. The existence of speed ramps and go slow signs, suggest that the people within the hospital were to be treated as different. The general appearance of the dilapidated, large buildings, indistinguishable from each other also suggested the residents were not worth a great deal as individuals in their own right.

Respect Shown To Man With No Learning Difficulties

Harry has established and maintained a valued role within his community. He has the respect and trust of a number of people. They talk to him as an equal about a wide range of subjects. They invite him to their homes and visit Harry by invitation. Harry also has access to resources that the three men could never have. Employment has played an important role in the resources open to him now. Harry also knows he has people like his daughter to go to for advice, although being able to make his own decisions appears important in retaining dignity.

"I like to make my own decisions about what to do, but if I have trouble with things like bills, then I go to my daughter for advice when things get complicated".

He is not embarrassed when needing help from people who are close to him.

Power

Means having real control over what happens to you

The Three Men In The Community

In general it was found that the choices offered to, and control exercised by, the three men were limited as shown in Table 4.

| | Type of Choices/Activities | Men Told to Make Choice | Choice made by: |
|-----|--------------------------------------|--------------------------------|-----------------|
| 1. | To wash clothes | Told by care assistant | J |
| 2. | To tidy up previous night's mess | Told by care assistant | B |
| 3. | Food eat for dinner | Asked to make choice | F, J, B |
| 4. | Watching TV instead of eating | Own choice | J |
| 5. | Smoking | Own choice | F |
| 6. | Going to pub | Own choice | B, F, J |
| 7. | Going to supermarket or post office | Asked to choose who goes where | B, F, F |
| 8. | Whether to buy new clothes | Asked to make choice | J |
| 9. | Pushing supermarket trolley | Own choice | F |
| 10. | Buying different food | Asked to make choice | F, J |
| 11. | Eating selection of food | Asked to choose what they want | B, F, J |
| 12. | Whether to buy new furniture | Asked to make choice | F |
| 13. | To go to the barbers | Asked to make choice | F |
| 14. | To buy a new TV | Own choice | F |
| 15. | To buy new shoes | Asked to make choice | F |
| 16. | To walk to post office | Told by care assistant | B, J |
| 17. | Buying chair, shoes, slippers | Asked to make choice | F |
| 18. | Buying a drink | Own choice | F |
| 19. | Buys picture for room | Own choice | F |
| 20. | Going to pictures | Own choice | J |
| 21. | To take a bath | Own choice | J |
| 22. | To buy a takeaway | Asked to make choice | B, F, J |
| 23. | Going to takeaway | Own choice | J |
| 24. | Getting cookery ingredients | Told by care assistant | B |
| 25. | Carrying cookery ingredients | Told by care assistant | B |
| 26. | Ironing | Told by care assistant | J |
| 27. | Cleaning rooms | Told by care assistant | B, F |
| 28. | Making dinner, what food eat | Asked to choose | B, F |
| 29. | Decision to go to bed instead of eat | Own choice | J |
| 30. | To apologise for his mood | Own choice | J |
| 31. | To buy cigarettes | Own choice | F |
| 32. | To buy sweets | Own choice | B, J |
| 33. | When to go to bed | Own choice | B, J, F |
| 34. | Make a drink | Own choice | B, J, F |

Table 4
Choices and decisions made

(Main activities and choices observed. Although some occurred more frequently, each has only been listed once. Observations were made whilst working shifts throughout the week. Therefore approximately one third of one week was observed).

Of these choices and decisions, less than half were made by the men themselves, although these were about aspects of living that might be expected to make a real difference to them. Sometimes the men were asked to make choices, which may be an important step in helping them make their own choices. At other times, though, staff would tell the men what they were to do. All these instructions were linked to the men being more involved in household and domestic tasks. Whether they did the activities, or whether someone else did, may be irrelevant to their quality of life.

On other matters, their views are crucial. One of the care assistants said:

"Jim doesn't want to go back, he was watching *One Flew Over The Cuckoo's Nest* the other night and said 'don't send me back there'".

Other staff think Brian and Jim would rather be back in hospital simply because:

"It's so much easier to be told what to do rather than having to make a choice for themselves, which is what happened in hospital".

The extent to which the men really influence what happens to them is limited. Over some matters they have no say, such as Brian and Jim sharing a bedroom, when it is clear that they do not get on.

The men's lack of experience of making decisions causes them some difficulties.

A member of staff said that:

" Jim in particular finds it difficult to make choices because he never had to make them before and they were just used to having everything organised for them".

"For Fred, however, it has been successful, he enjoys making choices sometimes; other times he doesn't seem to be bothered".

Getting the men to make choices was also difficult. The choices they like to make are small.

Brian's wishes have to be curtailed by his capabilities and this limits his ability to exercise choice. As a care assistant said:

"I think it's really been too much for Brian, he wants to do too much but he can't, he's limited too much by things like his road sense".

The difficulties of helping people extend their choice beset resettlement as a whole. The network manager said that:

"We do get people faced with too much choice and too much freedom before they are actually ready. This has to be put alongside the necessity of trying to ensure that choices people make are informed choices. People have gone weeks and not had a bath because it's been their choice, and we're saying that isn't informed choice".

Choice Available in the Long Stay Hospitals

The men's lack of choice making abilities seems to be a result of a limited choice in hospital. As a care assistant said:

"They would just sit around and do nothing all day, they were just used to having everything organised for them".

The matter of the importance of the choices available in hospital was raised by a staff member when she said:

"It would be wrong to say that the staff at hospital never let them make choices, but these certainly wouldn't have been very big choices, or ones that occurred frequently".

Over things that did matter, the men had little choice. A hospital staff member was asked about the day work that occurs there, and answered the men had no choice. If the men were eligible for work and capable of doing something, then they had to go. In hospital they had little money and could not choose to buy a television, new furniture, new clothes and so on. Throughout the hospital, people's clothes were similar and the furnishings were the same.

Choice Available to the Man With No Learning Disabilities

Harry is very rarely asked to make choices like whether he wants to do either that or this, perhaps because he follows a similar routine every week.

"I normally do the same thing every week unless someone is ill".

Although Harry is capable of making choices about what activities he does, they rarely change from week to week.

Harry has nobody to ask him to make choices as do Brian, Jim and Fred. He also has nobody who tells him to do things without any choice, like cleaning the house, or doing his ironing, and he does neither of these things himself.

Capability

Means the resources to get the things done that matter.

The Three Men in the Community

It was observed that the men were competent with some skills more than others, and that sometimes they needed support to be competent, such as the aid of staff or technology, as shown in Table 5.

| Person | Activity/Skill | Personal | Supported: Staff | Supported: Technology |
|---------|--|----------|------------------|-----------------------|
| B, J, F | Making own breakfast | + | | |
| B, J, F | Making dinner | | + | |
| B, F | Setting table | + | | |
| B, F | Washing up | | + | |
| J | Washing up | + | | |
| F | Crossing road | + | | |
| B, J | Crossing road | | + | |
| B, J, F | Ironing | | + | |
| B, J, F | Making cup of tea | + | | |
| J | Boiling kettle | | + | |
| F | Using public transport | | + | |
| B | Putting food in cupboard | | + | |
| B, F | Cleaning house | | + | + |
| F | Buying new items | | + | |
| F | Being responsible for new things | | + | |
| F | Putting new picture on wall | | + | |
| B | Eating food using knife and fork | | + | |
| F, J | Eating food using knife and fork | + | | |
| B | Measuring correct cookery ingredients | | + | |
| F | Being left alone in Education Centre | + | | |
| B | Making shepherds pie in class | | + | + |
| B | Putting cookery utensils away | + | | |
| B, J, F | Doing washing | | + | + |
| J, B | Putting items in washing machine | | + | |
| F | Loading washing machine | + | | |
| F | Using money | + | + | |
| B, J | Using money | | + | |
| J, F | Being left alone in house for about 30 minutes | + | | |
| B, J, F | Getting dressed | + | | |
| B, J, F | Having a bath/shave | | + | |
| B, J, F | Using toilet | + | | |

Table 5

A Summary of Personal and Supported Capabilities

(Observations were made whilst working shifts throughout the week. Therefore approximately one third of one week was observed).

Although the majority of the men's capabilities relied on staff support, they were observably capable of doing some things themselves, such as getting

dressed, making breakfast and making cups of tea. Jim and Fred could be left in the house for short periods. Fred was also beginning to understand and be able to use money and had basic road knowledge. Although he has more capabilities than the others, Fred was often reluctant to do things for himself, highlighting the need for constant support. As a member of staff put it:

"If the capabilities are not supported and promoted, they are lost".

The men needed staff support to help them make dinner, washing clothes, and for general hygiene, and also when getting out and about, crossing roads and using public transport. From observation, it would appear that attempts are being made to encourage all the men to learn basic cleaning skills and to try to do things for themselves. This is, according to a care assistant, largely successful:

"The men to an extent, now do everything for themselves. This was encouraged right from the beginning".

Attempting to do something was seen to be an important part of being capable even if the outcome was not completely successful.

For their capabilities to increase, the men would have to realise that they now have to try doing things for themselves. Different staff members pointed out some of the problems:

"Brian and Jim are so used to roaming around and having things done for them. They can't adapt well to doing things for themselves".

"Getting the men to involve themselves in the kitchen was also very difficult. Encouraging them to be involved and do things for themselves".

"... difficult making them understand they have to pay for things now like gas and food and that they are responsible for washing up".

Some aspects of capability were too hard for Jim in particular, to come to terms with, such as going out without the other men and being able to do things by himself. Whilst he is now able to go out without Brian and Fred, a care assistant noted that:

"There were many times at the beginning when we had to bring Jim back to the house because he couldn't cope with being out alone".

The men are now more able, as indicated by one of the staff when she said:

"They've come a long way with a lot of things - it might only be small things like making a cup of tea, but they are getting there ... it takes them months to learn, but it shows how limited they were in what they could do."

Considering the men had to do very little for themselves in hospital, it would appear that they are considerably more capable. However, some staff members

feel the men are expected to do too much, things that other elderly people wouldn't be expected to do, for example:

"It's all very well saying they are leading an ordinary life and are supposed to be using such things as public transport - but try getting an elderly person onto a bus with loads of shopping - you just can't do it. The majority of elderly people will get somebody to do the shopping for them or be taken by car by someone such as a relative."

This raises the question of what an 'ordinary life' is, and should be like, for elderly people, and whether this is, or should be, any different from ordinary life for people of any age.

Capability Shown in Long Stay Hospital

A large number of people in the hospital were observed to be either watching television on the wards, wandering around the grounds or sitting in the social club. Where activities were observed, these were packaging screws and making paper flowers, both in routine ways with one member of staff for 40 residents, making individual attention and skill development difficult.

This may be one of the reasons the men have limited capabilities upon leaving hospital.

Everything would have been done for the men in hospital from cooking food to having their drinks made, even having their food cut before they ate it so that they would not choke. One of the community staff who used to work in a large hospital said that:

"People from the hospital had little understanding of Brian's, Jim's and Fred's abilities, just as the men had no responsibilities, didn't have to do anything".

Capability of Man With No Learning Difficulties

Harry was more capable of living alone with limited support. He can clothe, wash and feed himself and is capable of helping other people, handling money and using public transport. He has little help with most things he does. People do come and check that he is looking after himself properly. He does little in the way of domestic tasks. As Harry himself acknowledged:

"My daughter calls and sees me a couple of times a week and does my main bits of washing, like my socks ... I have a home help once a week and she'll clean the house."

Harry is less able to look after his house properly and so has somebody to do the things he is less capable of doing.

Thus, the comparison is stark. The three elderly men with learning disabilities are being taught domestic tasks and spend considerable amounts of time on these: Harry, on the other hand, has people to do these things for him. Over emphasising domestic tasks has other, negative consequences. In telling the men to do these things, staff unwittingly exert their own power and authority over them (see section on Power, above).

Participation

Means being a part of a variety of personal relationships including those with close friends.

The Three Men In the Community

The sorts of relationships Brian, Jim and Fred had, and have developed are shown in Figures 2, 3 and 4.

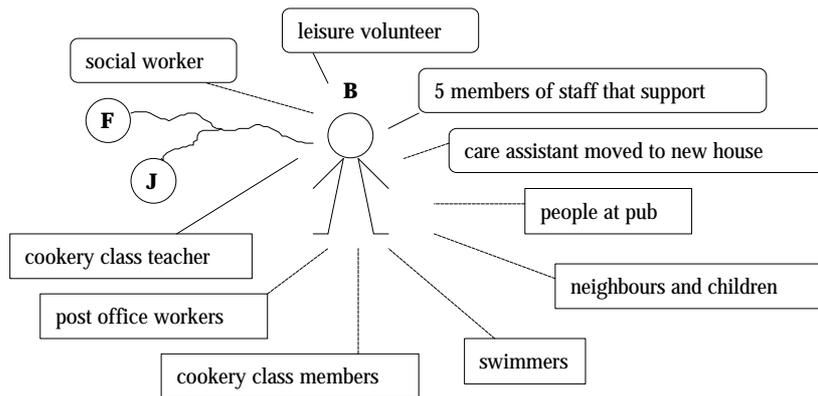
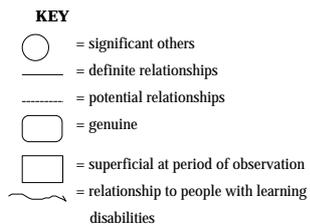


Figure 2
Brian's Relationships

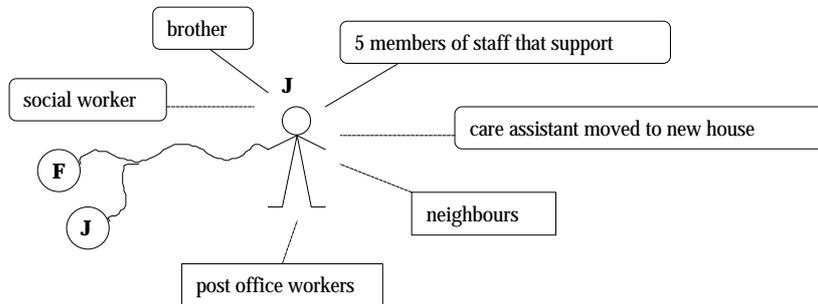


Figure 3
Jim's Relationships

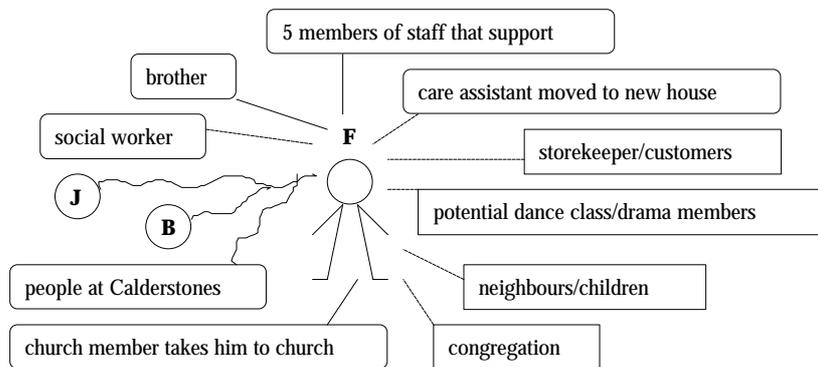


Figure 4 Fred's Relationships

There appear to be areas where possible relationships could develop particularly for Fred and Brian in terms of people at the classes they attend and possible neighbours, and for Fred the congregation within the church. For Jim as yet there are few potential relationships that are not with staff and that are not superficial.

Whilst observing the men there was little evidence of any concrete relationships forming. Neighbours would say 'hello' to all the men in the street, and people spoke to Brian and Fred at the Adult Education Centre. Even the men's own relationships with each other are tenuous; they did not converse with each other and Brian would sit in a separate room to avoid being hit by Jim.

The staff think it is important for all the men to get away from the staff and have occasion to mix with other people. However, this has been and still is, proving very difficult to arrange. Staff attitudes are not always helpful. When asked about the possibility of someone other than a staff member, taking Brian to cookery classes, a care assistant said:

"If somebody volunteers, it may not be a valued relationship, and anyway what are valued relationships, especially if they are with non-learning difficulty people".

Another member of staff gave her views of why people might be dubious about forming relationships with people with learning difficulties:

"Most people are frightened about the unknown ... easier to say that the men should be locked up instead of accepting that they are people and should be accepted as such".

Brian has demonstrated how once people have some contact with him they become more friendly. One of the staff explained how he went missing one day, went into a house across the street, and sat down with the family for a cup of tea. Whilst not endorsing the way he intruded, she pointed out that:

"The neighbours wanted something done about Brian because he roams around and now they don't seem that bothered."

Relationships Within the Long Stay Hospitals

The majority of contact the three men had in hospital was with staff and people with learning difficulties (who would only have been men for most of the time they were resident, as men and women were kept segregated until fairly recently).

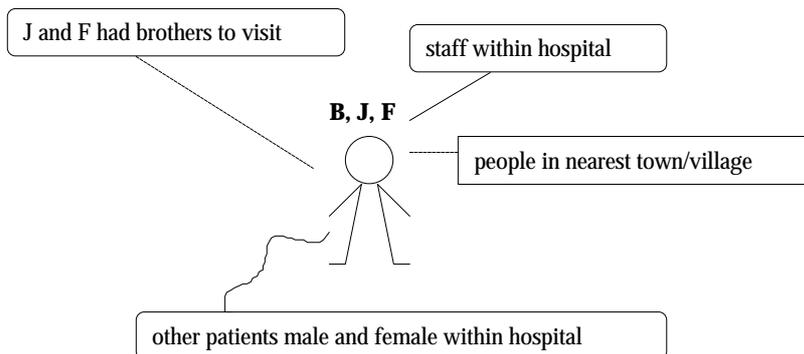


Figure 5
Relationships Within Long Stay Hospital

Visits to the nearest town would have been too infrequent for meaningful outside relationships to have been formed.

Relationships of Elderly Man With No Learning Disabilities

Most of Harry's relationships are well established and he mixes with a number of people, both male and female as shown in Figure 6. He has more links to his family than Brian, Fred and Jim. He has similar chances to form relationships through the activities he undertakes like shopping. The majority of his relationships would appear to be with people he has known for a long time, probably as far back as 40 to 50 years ago, mainly family, old friends and acquaintances from work. Few are at a superficial level.

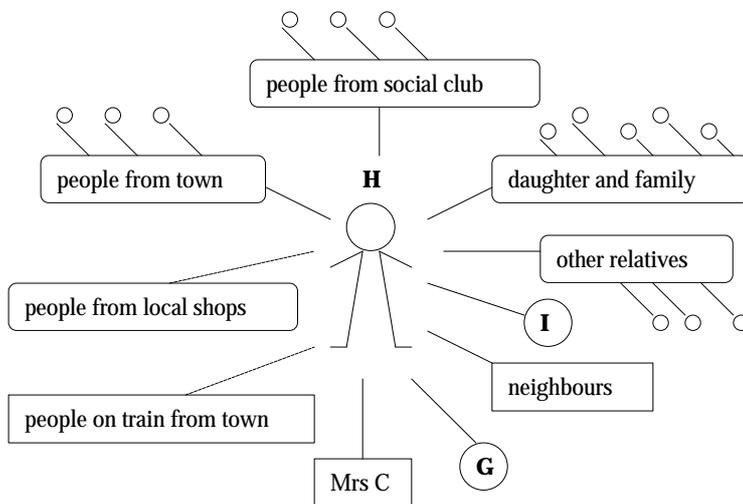


Figure 6
Harry's Relationships

Organisational Issues

The general view of some staff seems to be that they think Fred is benefiting from living in the community, but both Brian and Jim are finding it more difficult. However, overall, life is much better. One of the staff said:

"I would say not all things are positive, but they are having a better quality of life ... they should have been resettled years ago. I'd say some things are extraordinary but, on the whole, they live pretty ordinary lives ... you've got to make allowances - if they lived totally ordinary lives then the men wouldn't have learning disabilities."

Staff believed firmly that inadequate staffing limited the extent to which ordinary lives could be supported. More staff were seen as a necessity. One of the direct care staff suggested that:

"If every team had one extra staff it would boost the capabilities of everyone. There will be problems directly to do with the men as they develop and make choices that they can't be supported in, or that might be inappropriate".

There is evidence that this may be already occurring. Fred was invited away for a weekend with the local church but could not go because no member of staff was available to go with him. When staff were asked why he needed to be accompanied by a member of staff at all, no clear reply was given. Throughout the service there is an emphasis on support and help given by paid staff. The network manager echoed this view when she said:

"They actually do suffer a little bit you know, not because of the system but because we don't have adequate staff support to do all those things they want".

There is a strong argument that financial resources are too light, as put by the managers:

"It's supposed to be a needs led service and it actually isn't because of the financial constraints, we're actually identifying needs but we're unable to meet those needs within the budget we've got".

Overall Progress: 'Ordinary Living' for Brian, Jim and Fred

Each of the accomplishments will be discussed separately and then drawn together to reach a conclusion about quality of life for Brian, Jim and Fred since leaving hospital.

Presence

Presence in the community refers to the extent to which people with learning disabilities share places and activities with ordinary members of society. The men do share places common to those of other elderly people, such as using local amenities i.e., shops, post office. However, the frequency of these visits is sometimes limited to only once per day and normally less at weekends. Fred visits twice as many places as Brian and Jim and is more fully integrated in the community. This may be because he has more opportunities to meet with people, but is confounded by the fact that the other two men have more extensive learning disabilities. For Brian and Jim different kinds of support may be required.

Nevertheless, there is evidence that all the men are known within the local vicinity, such as in the shops and by neighbours, and are accepted. Brian and Fred go to evening classes and so they have chances to interact with other ordinary people.

The men certainly have more opportunities to meet other people than they had in hospital. However, their community presence falls short of Harry's. Harry has set places he goes to regularly and visits a much wider variety of places than Brian, Jim and Fred do, on a frequent basis.

Thus for the men to be leading a more valued community lifestyle, it may be useful to establish a routine, so that they visit the same places on a regular basis rather than every now and then. People from the community would be able to interact with the men more frequently, and stronger links to the community may be established. This may enable Brian, Jim and Fred to participate more fully in the life of the local community.

Respect

Respect and dignity refers to the extent to which the men are treated as worthwhile and valuable members of the community. The men are given respect, to an extent, by it being clear that they actually live in the house rather than the staff, who are there to support them. Opportunities for the men to be acknowledged as individuals, with their own abilities and preferences were limited. Until people with learning disabilities meet more people without learning disabilities, it is unlikely they will be treated as individuals, and thus

will be on the receiving end of negative attitudes and lack of respect which will hinder progress towards living ordinary lives in the community.

Staff attitudes to the men were mixed although most believed it was right they should be given the chance to live in the community. At times the men were reprimanded if they behaved unacceptably - this was usually accompanied by an explanation of why they should do things differently. Occasionally, staff talked about the men whilst they were present, which conveys a degree of disrespect.

The men did not value each others company and were often in conflict. This may be inevitable in any form of communal living, even on a domestic scale. However, since the men spend the majority of their time at home together, a major source of dignity will be the behaviour of the other residents.

Community attitudes are inextricably linked to both environments and staff behaviour. The complexity of this relationship was illustrated when Fred went to buy shoes. As his feet were small, he was served in the children's department, on a different floor from the men's. Staff were angry that the assistant treated Fred as a child. However, if he had been taken to a shop where men's and children's shoes were together, he need not have been served in a separate department. This incident highlights the challenge facing staff to try to ensure that the men are offered valued experiences, which involves considerable skill, foresight and planning.

It is difficult to assess how the respect and dignity that is being shown to Brian, Jim and Fred has improved their quality of life. Although they are experiencing more positive lifestyles, they are not as fulfilling as that of the elderly man without learning disabilities. Harry is made to feel worthwhile by helping others who are less able: his social life focuses on past employment which has meant he is valued by others and can still retain respect and dignity. Such positive resources and opportunities to play worthwhile roles have not been available to Brian, Jim and Fred to date, and so perhaps limit how much they will be valued by other people.

Power

Power refers to the extent to which people have choice and control over things that are important to them.

The types of choices Brian, Fred and Jim make for themselves are relatively minor, although they are beginning to exercise more meaningful control. Brian still relied on others to ask him to make choices. Sometimes staff directly controlled the men and told them what they were to do, especially regarding domestic chores. Interestingly, Harry is able to choose not to do the very things that Brian, Fred and Jim are told to do.

Even if their choices are limited they are on the whole, able to exert greater control over their lives in the community than they did in hospital. Brian may now be limited to some extent in the exercise of choice: in hospital he often

chose to wander around the grounds. Now his options to 'wander' are mostly limited by staff availability. Potentially though, he may now be able to join community groups such as the Ramblers, if links can be formed, which will widen his experiences.

The men seem to be limited in their abilities to cope with too much choice and therefore this will influence the control they have over what happens to them. Suddenly having the opportunity to make lots of choices after 50 years of few, would be difficult for anyone to come to terms with. However, 8 months into resettlement the men do seem to be coping more with this, particularly Fred who is now deciding to buy things like a television for himself.

For the men, making choices are a big step forward which benefit their quality of life. Harry often makes choices without thinking and because of his routine lifestyle, is not continually aware that a choice has been made. It is, perhaps, a disadvantage for Brian, Fred and Jim that their lifestyles do not seem to follow a set routine and are possibly faced with more choice than that of other people their age. The choices made may seem trivial to a person without learning disabilities, such as deciding what food to eat or whether to go to the shops or the post office. Nevertheless, they may be important first steps to more meaningful choices.

Capabilities

Do the men have the capabilities to get the things done that matter? The skills the men have are limited, and they would not be able to manage without 24 hour staff support.

However, all three of the men have become more skilled since resettlement, particularly in terms of what they do for themselves, even if they cannot always accomplish tasks without help. Considering that the men had to do very little for themselves in hospital, it would appear they are more capable, and are acquiring new skills since leaving hospital. In hospital the men were unable to recognise their own potential to do the things that people without learning difficulties do, because there was very little opportunity. Their lifestyle was organised around hospital routine, and it would seem that there was little understanding of the men's capabilities. As the men were never expected to do much in hospital, then it is only natural that problems will have occurred upon first being resettled, but with staff support these are beginning to subside. Thus with greater opportunity for skill development, by living in the community, the men's developing capabilities contribute to increased quality of life.

Although the men are developing more skills, many of the skills learnt are minor ones. Furthermore, they are not necessarily those skills important to elderly men without learning disabilities. For example, Jim, Fred and Brian are expected to clean the house, whereas Harry has a home help because he can no longer cope as well with these tasks.

Similarly, Jim, Fred and Brian undertake weekly shopping trips, by bus, whereas Harry shops locally every day for a small number of items. Perhaps skill development is being encouraged for Jim, Brian and Fred that is more appropriate for younger people. If the three men were supported in the development of age - appropriate skills, they may also derive other benefits, such as greater local presence, road safety awareness, daily planning and choice of food and possibly increasing the likelihood of building relationships. Whilst the 'weekly bus trip shop' may be beneficial, people will get to know them better if they shop daily for things on a smaller scale.

Participation

Are the men part of a variety of personal relationships? From the study it can be seen that Brian and Jim have very few meaningful relationships other than those of staff. The men have lived in the community for 8 months and no new strong relationships have developed.

The staff themselves may inadvertently be hindering the development of new relationships. They understand the need for the men to mix with other people beside each other and staff; however, their concern about valued relationships could mean they are being too protective of the men and discouraging people to get to know them. Some of the staff reaction may be linked to the absence of Departmental policy about relationships and risk management. It will be essential that staff work in ways to foster and encourage the inclusion of non-paid people in the men's lives, in the context of clear guidelines and back up by the agency they work for.

Harry spent a lot of time with people he has known - relatives or friends, for a long time. Jim, Brian and Fred on the other hand have been cut off from their past life and people they used to know in hospital. To remove the men from the hospital after 50 years and to cut contact with people they knew for this length of time, is something that would not happen to most people if they moved to a new area. Greater effort could be made to sustain important past relationships.

The men do have more opportunities to form relationships with people without learning disabilities than they had in the hospital and thus have increased potential to form relationships. Although this has not yet occurred to any great extent, in the future it is likely that the chance for new relationships to develop will be greater as the men develop.

How Useful Are the Five Accomplishments for Assessing Quality of Life Following Resettlement?

In many respects, resettlement of Brian, Fred and Jim has led to improved quality of life in terms of presence in the community, choice, power, capability, dignity and respect, and participation. Certainly the three men live more varied and full lives than they were able to in hospital. The gap between Harry's lifestyle and their lifestyles has begun to be bridged and the three men definitely seem better off.

They are developing presence in the community; are slowly being acknowledged as people who are entitled to an ordinary life as much as anyone else thus being shown the respect and dignity that is given to any other person without learning disabilities; gaining opportunities to make decisions and control, to an extent, what happens to them; are steadily becoming more capable in what they can do although this does sometimes appear to be inappropriate to men of their age; and they have more occasion to develop relationships now that they live in the community, although the actual formation of meaningful relationships has been limited.

Although their lifestyles had improved, it is clear from this study that the men still have needs that are not met despite living in homely environments, having access to community facilities and staff support. The paucity in relationships underpins achievements in all the accomplishments. Without a wider range of people available to get to know, and offer support to, Brian, Jim and Fred, progress towards more fulfilled lives will be slow. Staff suggest that higher staffing levels would enable the men to experience more opportunities, go to more places, exercise and realise more choices and so on. Whilst this may be true, higher staffing levels may further inhibit the development of other kinds of relationships. Instead of increasing staffing levels, progress may be speeded up by enlarging each man's own network of relationships.

Some accomplishments are being concentrated on more than others. For instance, due to the large amount of time that seems to be spent in the house, choice and capabilities around household tasks, seem to be concentrated on more than developing presence in the community and new relationships. The latter may be more appropriate to older men, rather than the development of skills such as cleaning.

Conclusion

The five accomplishments do not stand as yardsticks for assessing quality of service supports for better quality of life in a vacuum. They are useful in identifying general facets of the experience that contribute to integrated community living. They must, however, be anchored in an understanding of how other people in particular social categories live. In this study, the anchor

was the patterns of life lived by an active man without learning disabilities of similar age. If there is no recognition that different things are important in different ways to people of different ages, the five accomplishments stand in danger of becoming general principles that fail to direct service activity, or that are used to justify distortions in service supports. The result can be that highly principled, well meaning services support people in relatively unimportant activities.

We have seen that living in the community is possible for elderly men with learning disabilities, but that some social validation in terms of how other, valued, elderly men, live in the community is essential. A full understanding of life for elderly people without learning disabilities is required in order to give services a focus for the supports they offer to elderly people with learning disabilities.

Recent legislation in Britain on Community Care for elderly people is built on the knowledge that most elderly people **want** to continue to live in the community and do not want to enter residential care. Modelling services and supports for elderly people with learning disabilities on those for people without learning disabilities should dispel any notion that they should be offered large scale accommodation in elderly people's homes and that irrelevant tasks and activities are to be encouraged. It should also lead to serious consideration of making service supports available to elderly people without learning disabilities also available to those with learning disabilities. If Brian, Fred and Jim had a home help, for example, to help with domestic tasks, support staff could focus their activities on enabling the development of meaningful relationships with local people.

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Appendix 1

The Five Accomplishments

Presence in the Community

Means sharing places and activities with ordinary members of society. Community life is organised around a variety of ordinary places such as, the home, workplaces and educational establishments, leisure resources and shops, public buildings and public transport. People with disabilities are in danger of being separated from places like these through segregated settings, activities and timetables.

Respect

Means being seen as, and treated as, a worthwhile and valuable member of the community. Respect and self respect are linked to having a positive identity, and this depends upon having resources and roles that lead others to respond positively. Without such valued roles and access to resources people with disabilities are in danger of being trivialised, stereotyped and despised. Respect means having more roles than that of 'client'.

Power

Means having real control over what happens to you. It covers both ordinary everyday things such as what to wear as well as major issues as who to live with. People with disabilities are in danger of having few options available, of remaining passive, and unable to influence what happens to them. People with severe disabilities can challenge our ability to detect and respond to their preferences. Where choices do have to be made for people, safeguards should exist to prevent such decisions being made against their interests. Power and choice are not exercised in a vacuum, but in relation to the other four areas of quality of life, and in relation to the interests of others.

Capability

Means the resources to get the things done that matter. People with major disabilities are in danger of their personal incompetence being emphasised through a failure to supply the necessary expectations, instruction and assistance for achieving personally relevant goals. Capability depends on both a person's own competence (Personal Competence) and that of their environment (Community competence). Personal competence depends on general development of competence, knowledge and experience, physical and mental health and specific functional skills. Community competence includes practical or emotional support from others as well as provision of relevant technology.

Participation

Means being part of a variety of personal relationships, including those with close friends. People with disabilities are in danger of having few relationships, most of which are with clients, staff of services, and (not always) family members. Many of these relationships will be temporary and superficial.

The accomplishments do not necessarily have equal weight for all people at all times - for a person in a long stay hospital, Presence in the Community is likely to have the highest priority, creating the opportunity for the other four things to become a reality, given the right conditions.

These Five Accomplishments set high standards reminding us how poor is the quality of life of many service users and challenging complacency in even our best services. Taken together, they mean a life that can be seen as more than mere clienthood.

Appendix 2

Summary table of recent relevant research into resettlement for people with learning disabilities

| Author/Date | Aims | Method | Subjects | Findings | Critique |
|----------------------------|---|---|----------------------------|---|--|
| Beswick et al 1990 | Evaluate care and quality of life in the community. | Matched subjects design to assess changes over a 5 year period. | N=50 Age=21 to 84 years | Subjects moving to community showed and maintained more improvements than subjects remaining in hospital. | Longitudinal study. Subjects assessed every 6 months, may have meant some validity was lost in showing difficulties that occurred and impact of local services on community integration. |
| Dhooper et al 1989 | Examine every day activities of group residents Explored different types of houses. | Interviews-Questions instrument about activities. | 50 adults | Overall satisfaction with life by most residents. Basic needs being adequately met. Subjects wanted to try greater variety of activities. | Little evidence of how often certain activities occur. Frequency of events. Study explored only a few dimensions. Need more research into every day life experiences. |
| Evans et al 1987 | Evaluated impact of ordinary housing for individual people. | Direct observation diary of activities during the day. | N=4 females | Majority of time spent in living setting. Increased domestic activities, decreased recreation activities. Benefited from move. | Did not examine areas such as choice and relationships with people without learning disabilities. |
| Felce et al 1985 | Examine change in behaviour on transfer from institution to small homes. | Environmental inventory and observation Experimental group in houses already. Control group in process of moving. | N=12 | Residents in small homes lived in more enriched environments. Greater opportunity for activities and staff/client interaction. | Doesn't include problems that occurred. Ignores wider issues such as choice, relationships. Does more enriched environment mean better quality of life? |
| Felce et al 1986 | Compare activity of staff and clients in different residential settings. | Observation in larger and smaller settings. | N=50 | Greater client engagement in appropriate activity, increased staff/client interaction in smaller settings. | There is more to quality of life that observation alone will not show. Activity is only one aspect of Quality of Life. |
| Hulbert & Atkinson 1987 | Comparison between old and newly resettled groups. | Repertory grid technique. | New group=6 Old group=6 | Newly resettled group happier than older group. Older group less concerned with domestic activities. | Technique provides information about peoples feelings. Does not provide a full picture of Quality of Life. |

| | | | | | |
|--------------------|---|---|---|---|---|
| Joyce et al 1989 | Diaries as an alternative to observation. | Staff kept diaries, recorded main activities. Video made to sample different periods of diary taking. | N=3 female | Agreement between diary and observation. Results more accurate when person engaged in activities for a length of time. | Limitations in accuracy of diary recordings. Diaries alone don't provide information about ecology and organisation of individual life styles. |
| Shah & Holmes 1987 | Examine effects of new placements on lifestyles and behaviour of movers. | Structured interviews to measure life styles and relatives opinions. | N=41 movers N=42 controls stayed in hospital | Improvements in care not always associated with improvements in behaviour and skills need for high level of staffing. | Examined move to quite large hostels rather than small residential setting. Likely to be problem of inadequate staff levels. |
| Singh et al 1989 | To show positive outcome of rehabilitation for elderly people with learning disabilities. | Scored subjects on social training achievement record (star). 16 skill categories for independent living. | N=4 females | Over period of 5 years encountered no significant problems. Involved in social activities and received community support. Did not wish to return to hospital. | Subjects had only mild learning difficulties and selected on this criteria. Nurses introduced them to the community. |
| Stanley & Ray 1988 | Investigated quality of life as an alternative to quality of care. | Questionnaires measured-dependency and community participation, frequency and satisfaction. | N=114 100 no learning difficulties 7 hospital residents 7 in group home | Environments not significant different between hospital and group houses. Quality of life scores lower in hospital. People in group home had satisfaction score almost equal to people without learning disabilities. | By asking local community study overcame bias of researchers subjective views. No observant evidence that people in the community actually did everything they said. May be adverse effects of drawing community attention to people. |
| Thomas et al 1986 | Compare quality of life for residents before and after transfer from hospital to community. | Observation over 12 month period of subjects pre and post placement. | N=76 | Overall quality of life improved i.e. more comfortable accommodation, levels of activity low in community. Also social contact low. | No evidence of personal feelings about move from clients or staff i.e. happiness, hopes or aims for each subject. |

