

CHAPTER 6

**Richard Oliver, Margaret Tarrant,
Elizabeth Shaw, Kathleen Wright —
a variety of issues**

We have given a full account in the preceding chapters of the changes for four people in order to illustrate how attention to a wide range of quality considerations can be coordinated to take account of individual needs. For Richard, Margaret, Elizabeth, and Kathleen we intend to highlight just one or two of the major issues relating to their involvement with 10 Summerton Road; selecting some of the key elements in what coming to live there has meant for them, rather than giving a comprehensive description.

Richard Oliver: even if it is a higher quality service, it is still the only choice

In highlighting the advantages over what has gone before, it is easy to get perilously close to arguing that the new alternative is undoubtedly the best. We need to avoid falling into this trap. It is still the case that the usual service response to someone who requires additional help to live an adequate home life is the offer of a place in a group residential setting rather than an attempt to provide supportive arrangements in the person's home situation. People with mental handicaps, whether they are offered a high or poor quality option, tend not to have a real choice between alternatives; only the ability to accept or refuse the service offered.

Richard Oliver lived in 10 Summerton Road for just five months. His story illustrates the straight-jacket of service response; something which even small housing developments do not change. 10 Summerton Road, although smaller than most, is still a group setting. The service emphasis is still on the provision of a single building by which the needs of several people are to be met. It does not respond by designing the optimal residential service arrangement as needed by each person individually. Of its type, the house might be considered to be an example of a high quality facility; but there are limitations that should be recognised concerning what such a type of facility can achieve. The people

who come to live at 10 Summerton Road are moved from where they lived before, away from the very local ties they may have had, into a service building, the nature and location of which remains permanent and unchanging even though the individuals it serves change from time to time as do the staff who care for them.

Richard transferred to 10 Summerton Road from a small mental handicap hospital in a converted Victorian workhouse in November 1982, twelve months after the house opened. Although he was elderly, sixty-seven years old, he had only been admitted to residential care at the age of sixty-five; indeed that was the first time he had been diagnosed as having a severe mental handicap. His presenting problem in contacting the health services was a serious skin complaint. As a result he was diagnosed as having Down's syndrome and transferred into the mental handicap hospital services.

Richard had spent his life in one of the small villages near Merton. There his family owned land and derived income from it. Richard lived within the family set-up and performed a useful role, helping in a simple way with the agricultural work, for example, leading and tending the horses. Despite the fact that Richard had Down's syndrome, perhaps the most identifiable set of physiological signs most consistently indicative of severe intellectual impairment, it had never been recognised that he was mentally handicapped. He was known to be deaf and therefore an explanation existed for his lack of language; his slowness in other ways and his refusal to do what might be asked of him was put down to stubbornness, allied to a degree of simple-mindedness. When he was in his sixties, Richard had a bad occurrence of dermatitis which was allowed to gain hold over his entire body. This caused serious flaking of the skin and soreness, particularly on his face, fingers, and feet. He was admitted to the acute hospital for treatment where he was identified as having a severe mental handicap and, as a dramatic example of rigid categorisation, transferred to the mental handicap hospital sector.

There are a number of remarkable facets in Richard's story. Firstly, the fact that he had spent sixty years of his life, albeit in a tranquil rural backwater, without being labelled severely mentally handicapped, illustrates well that notions of handicap are not absolute but relative to particular social situations. Secondly, in marked contrast, the acute health services responded as if the mental handicap rather than the skin complaint was the

paramount concern. Thirdly, it illustrates that former workhouses and other large, old-fashioned institutions, which were brought into the National Health Service and titled "hospitals" on its foundation, have become accepted as a source of specialist services despite the manifest shortage of a variety of resources, including those as basic as an adequate physical environment and a reasonable proportion of trained staff. Of course it may be convenient in some quarters not to look beyond the veneer of the official title. There is often open recognition of the inadequacies of the long-stay mental handicap institutions. But at the same time, the use of vague terms such as "hospital" in phrases such as "the need for hospital care" can conjure an impression of high standards of health care delivery which are specially designed for people with mental handicaps and are, therefore, better than those that could be obtained from generic community services. Our experience as set out in the earlier chapters, and from past research, shows the reality is somewhat different. We become too concerned with inventing categories by which to pigeon-hole people and titles for services to match the categories. In the case of Richard, our own involvement in the small home service was not free from this fault.

Richard suddenly found himself in a poorly staffed and old-fashioned facility for men with mental handicaps, on the edge of a village on the other side of the health district in which he lived; a victim of inter-consultant referral. The skin complaint was not the only contributing factor to his situation. He was growing old, parental support was no longer available, and his elder sister with whom he lived was beginning to have more difficulty in managing. But the laziness of the service response should also be seen as possibly the primary contributing factor. When members of the responsible mental handicap services management team other than the psychiatrist were alerted to his situation, they responded to the inappropriateness of Richard's placement. But ultimately the service failed to respond well to the needs of either Richard or his immediate family. Had the route into service involvement been other than that which occurred, it might have been possible to replace or add to the family support which had allowed Richard to be a member of a village community all his life. As it was, he embarked on a new home life in his retirement.

The institution to which Richard was sent was designed in the last century as an ideal environment in which to supervise the

provision of cold comfort for the destitute and other disadvantaged people. Despite conspicuous efforts by the district health authority which inherited its management in 1974 to revamp this environment, it still retained much of its original character. It was arranged in three ward blocks on three sides of a central quadrangle. These three wards at one time housed up to eighty-six men, but numbers have been actively reduced in the last few years. Accommodation was rudimentary — large rectangular dormitories, large day-rooms with chairs in ranks, and a single, separate dining room for the entire facility. Toileting and washing facilities were similar to those in public buildings. Some attempts had been made in recent years to provide better accommodation, for example, by converting the chapel and surrounding small rooms into a self-sufficient flat for the benefit of a few of the residents. But such changes could only have a marginal effect. The overwhelming impression was of a barren environment, exemplified by the fact that the internal walls were painted, unplastered brickwork. Some of the staff were aware of today's more progressive philosophies, involving encouraging residents' independence and participation in community life. However, although staff tried to encourage some of the residents to visit pubs in the village, the village was too small and too smart to be able to cope with so many, rather bedraggled, institutional residents. There was no disguising the fact that these people were, in all senses of the term, on the edge of society.

Richard had remained in this facility rather than 10 Summerton Road, which was at least local to his previous address, because he was not at first considered to be sufficiently handicapped to merit the intensively staffed health service contribution to the comprehensive range of community services, which was how this new house was defined. In other words, Richard did not fit the category which was used to decide who would be offered this improved service. This kind of rigidity is inherent when service provision is so inadequate that judgements about who can and who cannot receive it have to be made.

Richard moved to 10 Summerton Road following a reassessment of his abilities and a change in opinion: he was considered to fit the eligibility criteria after all. He had at first been assessed as being able to eat, wash, and dress independently in the institutional setting, and to be fully ambulant with no behaviour disorder. It was, therefore, felt that responsibility lay with the

local authority social services department to make suitable local provision for him. However, the early assessment was misleading. For example, Richard's ability to dress himself fully was dependent on a supply of loose-fitting clothing and elasticated trousers. He was very deaf and had no spoken language. Deemed to be eligible for 10 Summerton Road after all, he became the fifth person to move into the house on a permanent basis.

Making the best of a bad job

Richard only lived in the house for five months. At the age of sixty-seven he stumbled and fell, breaking his femur. Surgeons decided to operate and pin the bone. Richard died twenty-four hours after coming round from the anaesthetic. There was some speculation afterwards that he may have had a congenital heart defect. Our knowledge of his previous family life is sketchy as we only knew him and his family for a short time. But it can probably be said with a fair degree of confidence that life for Richard, even in the unusually enriched and progressive form of residential care provided at Summerton Road, was a second-best solution compared to his continuing to live to the end of his days among the family and circumstances he had always known.

It is hard to imagine what the impact on Richard was in moving from his family home to a mental handicap institution. In terms of personal ability and personality he probably remained relatively unchanged, being much the same in terms of skills and interests as he was when he later moved back to Merton. We are confronted again in Richard's story, as in other people's stories, by the fact that a person's life style, daily living opportunities, and membership of an identifiable community, are not wholly dependent on that individual's abilities, even where the person is considered mentally handicapped. It is not the mental handicap that causes the life style, the lack of opportunity, or the separation from the mainstream of society that can be occasioned by admission to a residential service. These are shaped to a considerable extent by the characteristics of the service provision itself.

In the short time that Richard lived at 10 Summerton Road no-one would claim that substantial development of his personal skills occurred. However, his life style was able to be changed back to something closer to what he may have previously experienced: a person living with help in an ordinary house within a local

community. Richard's reversal of fortune points to a general lesson that must be learned in considering the residential placement of people with mental handicaps. Those individuals currently living in institutions do not necessarily have to be habilitated, that is, taught to be more able, *before* they can learn to live in community settings. Rather, community settings should be arranged to support such individuals, given the skills, interests, and personalities they currently possess.

Richard was of retirement age, was slow, and a little frail. He was ambulant, continent (with a few accidents), and able to dress himself if given help with fastenings. His fine manipulation finger control was not good and his ability to grip strongly was badly affected by the soreness caused by the skin complaint which was still causing him trouble. He was sociable, could understand speech if it were accompanied by gestural communication, but had no words himself or understanding of a formal sign language. He wore hearing aids in both ears. He appeared to be used to a traditionally male domestic role — sitting and waiting to be served his meals and drinks. He smoked heavily and liked a drink of beer. His skin complaint remained unchecked despite the considerable time that he had spent in the mental handicap hospital. Rather than seeking further advice to clear the condition, treatment there had been for him to wear white cotton gloves.

For Richard the main contribution of the local housing service was to embark in the direction of re-establishing his community and family ties, establishing a useful role for him in retirement within the house, and meeting his basic needs effectively. Thus his hearing was checked and hearing aids adjusted, spectacles were obtained, and treatment of the skin condition was assiduously followed. When consistent application of the lotions did not bring improvement within a short period of time, a second consultation was obtained with the original specialist. A changed régime of treatment was prescribed and followed and the condition cleared up. Moreover, Richard's personal appearance was generally improved from that which was tolerated in the mental handicap hospital. New clothing was obtained, much bought and supplied by his family, and care was taken over presentability: his trousers were kept pressed, shirts which required it were starched and ironed, and he wore a neck tie. During his first week after moving in, chiropody treatment was started. With a similar urgency, his dentures were checked and new ones obtained. To be perfectly

honest, no-one was quite sure whether he transferred from the mental handicap hospital with his own or someone else's false teeth!

Richard's sister, niece, and more extended family were very pleased that he was able to live locally. They were keen to be involved and to make sure that his interests were served. Richard was half-owner of a caravan park and his family were in full collaboration with the service to arrange a regular income so that he could enjoy the advantages of such a position. Family members visited the house, and service staff arranged for Richard to visit his sister weekly for lunch. About the time of his death, arrangements were being made for Richard to join the active old people's club in his old village, of which his sister was a member. As a retired man, Richard was a regular visitor to town, often accompanied by Mary who, like him, had no alternative day-time occupation. He shopped and went to the pub for a beer; he continued to smoke cigarettes.

Within the house, Richard began to develop much more active participation in home life. For him, it was probably a new role. He gave every impression that in his family life housework had been for women. However, he rapidly began to enjoy many routine domestic tasks: stacking and unloading the dishwasher, putting crockery, cutlery, and shopping away, simple dusting and Hoovering, peeling and slicing vegetables. He worked collaboratively with other people, such as Carol or Shirley, obviously responsive to their company and attempting to communicate by means of rudimentary sign language. Teaching of a formal sign language was begun, but there was insufficient time to make substantial progress.

Margaret Tarrant: release from institutional squalor

Two themes are emphasised in Margaret's story: the comparison of her previous institutional environment with that of the small home; and the views of her mother on both. Margaret became a boarder at a Rudolph Steiner School at the age of eleven-and-a-half, but sadly her behaviour in just six weeks proved too difficult. Unfortunately, no other suitable school could be found for her, so Margaret was admitted to a long-stay mental handicap hospital. As a young adult she had lived on the female

locked ward of that hospital. She therefore had lived among people considered to be disturbed, viewed as beyond hope; people to be confined on the “back ward” away from not only ordinary community life but also the already segregated society of the remainder of the hospital. Fortunately for Margaret, her family moved into the catchment area of 10 Summerton Road and about eighteen months after the house had opened she was able to leave the institution, never to return.

In order to place the following description in context, we must honestly say that the ward on which Margaret was living is one of the most dehumanising, blatantly awful situations in which human beings live that we have ever seen. Not all mental handicap hospital wards are so poor. We have seen many better; but we have also seen worse, and others just as bad. We think it chastening to give a short, frank description of the impression of that ward as a challenge to the view that such conditions are a thing of the past, eradicated by the priority status that has supposedly been given to mental handicap throughout the last two decades. Our comparison with other wards which have better conditions is current and so too is our comparison with hospital wards which are worse. The ward where Margaret lived is not a rare relic of the past.

What a “locked ward” is in practice varies. In some cases it means that the external doors are kept locked and residents come and go only with staff mediation. In other cases it is simply an archaic term for a hospital ward where all the “difficult cases” end up and does not reflect an actual policy of locking doors. In others, and this was the case where Margaret lived, the emphasis on security is far greater, and many internal doors within the building are routinely locked in addition to those leading to the outside.

In Margaret’s ward, residents were collected and effectively penned during the day in the living room. Access to the rest of the ward was denied by locking doors to all other areas. When not in use the dining room, bathrooms, and bedrooms were also kept locked. The staff office, always locked when not in use, was even locked sometimes when staff occupied the room. Only staff had keys; keys were never left in locks. When the living room and ablution block doors were open, access to and from them was possible. Sometimes the toilets were locked and access was unavailable. However, even when access was available, staff help to assist residents to perform what they required to do was not

necessarily available. The care given to even the most basic individual needs — to use a toilet, drink when thirsty, eat when hungry, to have privacy — was minimal. The phenomenon described by other writers about institutional life of “block treatment” — the mass processing of groups of people together — was the mechanism for the dispensing of care. There were toileting times, washing times, mealtimes, dressing and undressing times, and bedtime; the same for everyone — and the requisite living areas were unlocked, used, and re-locked accordingly. Other than through these set routines, care was haphazard, resident initiated, and performed by residents to the best of their limited abilities. If a resident did not use a toilet when urinating, for example, then it was seen as being either because the person had not learned to do so or had learned not to do so; and the service had no structure or ability to guarantee staff presence to alter the situation.

The living room was one of the most unpleasant places in which anyone could wish to pass many hours, let alone every day. It was a large space with a hard, vinyl-tiled floor, separated from the dining room by a wooden “concertina” partition. The rudimentary furnishings comprised some plastic chairs, and some easy chairs typical of modern institutional provision with a wooden frame, webbing straps, and loose vinyl-covered cushions. One corner of the room, where the television was situated, was carpeted. There were some bright orange, vinly-covered sag-bags. There were no materials provided to offer any means of passing the day purposefully occupied. At times, urine and faeces were on the floor; the smell was difficult to bear. When we were there we saw people urinating on the floor and one woman manually taking faeces from her rectum and smearing them on the wall. We do not know whether staff saw the incidents we witnessed but, given that we noticed such occurrences during only a number of short visits, they must have been aware that their service promoted and tolerated such events. One resident displayed a marked problem behaviour: ripping the clothing off other people while they wore it; and several people physically assaulted themselves or others. We do not know whether such actions were seen by the staff on duty and allowed to continue without any attempt at intervention being made.

As far as we could see, the people we saw squatting to urinate in the living room were left unwashed afterwards. Some, no doubt, were sitting in urine-sodden clothing. Others did not have that

discomfort as they were in various states of nakedness anyway; either from the waist down or in a complete state of undress. Urine, and sometimes faeces, lay for quite a while on the floor until noticed and removed by staff. It is not surprising the room stank. We once saw a staff member, on seeing a pool of urine on the floor, go and collect a large linen sheet, cover the urine with it and allow it to soak in. She then took the sheet away. No further attempt was made to cleanse or disinfect the floor.

The major form of human interaction in the living room seemed to stem from some residents abusing others: being assaultive, removing or ripping others' clothing, removing others' shoes and throwing them away. In the main people showed extreme social withdrawal. Margaret herself spent long periods curled up on a chair, either holding her head and covering her eyes, or staring into nowhere; or similarly lying on the floor; or pacing up and down, twisting her hair round and round with her one good hand. At times she stopped to hit her jaw or nose with her fist and to shout out. Other people showed similar patterns of repetitive, withdrawn behaviour. One woman filled her day by pacing in a small circle holding one arm vertically in front of her and rotating her hand, helicopter-fashion, in front of her eyes. Another stood with her forehead resting on the wooden partition to the dining room, using it as pivot to allow her to rotate her trunk repetitively in alternating, semi-circular fashion. When we closed our eyes and just listened we could hear no conversation, no excited chatter, no signs of happiness; just sometimes the odd word called out, like "nurse", and mostly a low murmur of moans and whimpering punctuated by an occasional high-pitched scream or bout of screaming.

Toilets and washbasins were in a large ablution block with a marble floor. The toilets themselves were in cubicles; though partitioned, someone of normal adult height could look over the top of the dividers if they chose to do so. In all, the area was like a public lavatory. The half-glazed door to the foyer was usually open. The toilets were on the other side of the foyer from the living room door. There were open drainage gutters under the sinks which, when they were blocked by clothing and the taps were left on, would overflow. There was no toilet paper. The bathrooms were kept locked. They had no luxury or refinement about them in any way; just a free-standing bathtub in the middle of a tiled floor. In the central foyer, just outside the dayroom, a small, half-glazed

room had been created. This was used to seclude people who were behaviourally disturbed. We saw a person left in that room, beating herself and screaming, and in the process missing her meal.

Meals were served in the dining room, which was opened for the occasion, and which was the other half of the rectangle that constituted the day-time area of the ward. The food was not prepared on the ward. It came from the central kitchen in a heated trolley, from which it was served onto plastic plates and bowls in a room adjacent to the dining room and then passed through a hatch. Residents waited in chaotic fashion, some sitting, some generally milling about, and some standing at or near the hatch. While waiting for her meal, Margaret sat rocking backwards and forwards in her chair, tapping the front or side of her nose with cutlery. The meal was an unceremonious affair performing no more than the function of providing sustenance to hungry people.

Given this ambience, it is not difficult to imagine the repetitious, unstimulating, wasteful existence Margaret led. Moving to 10 Summerton Road provided a dramatic contrast, a radically different way of life, and a substantially improved role for her to fulfil. The detailed programmes which staff designed and followed in order to teach Margaret small, new competencies do not represent the substance of the major change; being only peripheral niceties in the contrast between her previous existence and her new one. The small home service has set teaching objectives and implemented programmes designed to teach Margaret new skills and to alter socially undesirable ones. Of greatest significance, however, is not the success or failure staff have had in affecting Margaret's behaviour, but in how such effort represents the service orientation. The desire to teach useful functional skills, to improve appearance through gaining elegant and fashionable clothing and hairstyles, and to teach "normal" social behaviour stems from a philosophy of promoting meaning in the life of the person who is handicapped: which culminates in a life of contribution to the running of the household and of involvement in the wider community world.

There are challenges inherent in such aspirations. There is no magical process by which the domestic and community-based characteristics of the new service seep through the pores of the skin of the person who is handicapped and generate in that person ordinary domestic and social skills, preferences, and standards.

Thus, following transfer, Margaret has retained ways of behaving and preferences which were part of her institutional past. She arrived at the house with a long-standing proclivity for holding and carrying objects — a teddy-bear and any small ornament. Her sleep at night is often disturbed; she sometimes wakes in a state of excitement, wanting to walk around, sing, and put paper and clothing down the toilet. She has thrown toilet paper out of the windows. She also has an obsessive interest in “tidying” the toilet paper into the toilet, causing blockage and flooding if flushed. She has unwound toilet rolls and put the paper down the toilet during the day as well as at night. She continues to have self-stimulatory habits such as singing, echolalia, and tapping her nose with cutlery or a finger. Outbursts of more violent self-injury did not stop the moment she crossed the house threshold.

All of these behavioural traits are still present today but they have been changed for the better: lowered in frequency, intensity, or duration. Her sleeping is much more reliable, her self-injury rare, and she no longer throws rubbish out of the window. She continues to put vast amounts of paper down the toilet, which is still problematic but only in terms of the economic and practical consequences! She has been taught which objects it is appropriate to pick up and carry, and where to take them to and put them down; and she no longer wanders round continually clutching some item between her body and her withered left arm. She no longer has long stretches of time to fill with no productive role or responsibility.

In terms of positive skill acquisition, teaching has been part success and part failure. Margaret is able to do many household activities with staff help. She can follow gestural prompts, has some receptive discrimination of spoken language, and has good persistence. Therefore involving her in, say, stacking the dishwasher or emptying, cleaning, and re-stacking the cupboards is easy. Teaching has been needed to give her skills which were not necessary to life in the hospital, for example, how to fill a kettle, how to hang clothes on a hanger, and how to put dirty crockery on the drainer to be washed rather than away in the cupboard. Given the previous absence of toilet tissue she has been taught how to wipe herself and, given the restrictions of life in a long-stay hospital, how to use public conveniences.

Important though such teaching is, and without wishing to diminish the staff achievement and skill in teaching Margaret, who

is evidently severely mentally handicapped and has certain autistic characteristics, it is not this kind of skill acquisition from which Margaret's improved quality of life derives. We return to our earlier observation that such programming is the icing on the cake in terms of its significance in Margaret's changed life. The more important change is that Margaret now enjoys the support and direction which enables her to be involved in the stuff of life itself. Indeed, it is much more likely that it is the higher quality of life that promotes developmental growth than that the developmental growth occasions a higher quality existence. Margaret moved from a hospital ward comprising large dormitory, large toilet area, large dayroom, large dining room, and no semblance of private space, to a house with her own bedroom. In her bedroom she has wall-to-wall carpet, a divan bed, wardrobe, dressing table, shelving, and a chest-of-drawers. More importantly, she has a door to close: autonomy to leave and join the society of others.

That sense of autonomy is extended through other aspects of home life of the people living at 10 Summerton Road. It includes the ability of individuals to meet their own basic needs, such as being able to go to the toilet when they choose and to be helped by staff tuition to do so competently; or being able to get a drink of water from the kitchen. It extends to the "more sophisticated" pleasures of life, such as being able to help themselves to a piece of fruit from the fruit bowl. Margaret's new life, like that of her companions has greater responsibility as well as greater autonomy. The house needs cleaning and tidying, crockery and cutlery need washing and drying, clothes need laundering, food needs to be prepared, and the people who live there and generate such requirements, need to meet them. In common with the others Margaret's daily activity has, at the least, such purpose.

Her new life also has a much greater appearance of social order. Margaret lives with six other people with mental handicaps who, with the aid of staff, collaborate with each other. Direct interactions between these individuals do not take up a major part of their day, as most lack the language by which to conduct such social behaviour. But people collaborate, in the sense of contributing to the accomplishment of the household tasks, by doing specific tasks in parallel (such as two people helping to clear the dining room tables, or two people doing the supermarket shopping with a member of staff) and by being considerate of each other (for example, passing a serving dish, condiment, or other

item at the meal table, or when making a drink getting one for someone else too). Positive interactions do occur and anti-social exchanges are rare. Also absent are the overpowering impressions of the previous environment in which Margaret lived: depressing noise, and bizarre, psychotic movement. That is not to say that the social milieu of 10 Summerton Road is always perfect: the people who live there do get cross with each other sometimes and respond with physical aggression as their only means of communication. Just as crossing the threshold did not generate instant change in Margaret, the same is also true for other members of the household. People spend time making strange noises and ritualised movements, Margaret included. But the extent and overall balance of impression is utterly different.

Keeping a household running, in the ordinary world at least, requires community contact and involvement in shopping. Respite from the chores of household life often also includes community involvement in the pursuit of leisure activities — going for a drink in a pub, or to activity groups or clubs. It is interesting that it is only when a person has a job, chores, or tasks to do that talking of rest, recreation, and leisure takes on any meaning. Margaret's new life includes such elements. She is often in town, so she needs to look good and she needs to learn how to socialise and how to behave so as to avoid generating adverse reactions. She takes pleasure from being out and about. She has joined a folk club which is held in a room of a local pub. She enjoys evenings there.

Other ways by which people derive purpose in their lives are through work and through the development of intimacy with those to whom they are closest. Margaret does not have a job outside the house, although it is not inconceivable that she could have one. But like most of us she has family. The remainder of this description of Margaret is given to her mother's account of the impact of the move to 10 Summerton Road. It is written in the order that the thoughts came to Mrs. Tarrant. It is as accurate a transcript of her actual words as our notetaking has allowed.

“The first thing you notice about the hospital — any hospital and the school in fact, well most large places but not here (10 Summerton Road) — is the smell. No matter how clean the place is on the surface, there is a smell that tells you that you are among people who are incontinent. It is the first thing you notice; you can't

get away from it. But not here, you never get that smell here. Some of the people are incontinent but the staff manage well. It's marvellous really.

The main difference is that Margaret has come back to her family. I used to visit regularly before; I tried hard but it was too difficult and too far. We used to have Margaret home but no sooner than we got her there, she would want to go back to the hospital. The journey was terrible, Margaret playing up all the time. And then at home she would play up wanting to go back. I didn't know how to stop it or control her. Now she comes to our home and we're in and out of this one. I run into her in Merton. That was a surprise the first time it happened. Just after Margaret had moved here, I saw her walking on the pavement in town with one of the staff. I hadn't expected it, such a normal everyday occurrence. I was driving at the time and I nearly crashed my car. Margaret is now back with the family — I feel it and everyone else at home too, including her sisters; she has a large family, lots of sisters. I used to try to visit her before every week but a visit to hospital is always artificial; it's a special thing a visit. But now she's included in ordinary family activities. It's absolutely wonderful. I feel I am involved in her life again. I did try and the hospital were very good, they tried to let you be involved. I even took washing home. It was no good though because I never saw her wearing the things again, they just disappeared.

Margaret looks better now and her standard of behaviour is much improved. I suppose that they expect so much from her here, she has to get better. I used to be nervous having her with me or at home, she used to play up and I didn't really know what to do. It was so upsetting. I feel better now. She used to scream non-stop and smash things up — she broke two televisions before she went into hospital. In hospital they filled her up with tranquillisers. That can't do anybody any good. Now I can say, "Peggy, sit down a while", and she does. I think she was probably maturing all the time. She went to the hospital as a child and came here as a young adult. But nobody at the hospital told the right story. I would tell them that I would have difficulty with her screaming and they would say that Margaret didn't scream there. But she did, I saw her many times. There was the time she fell and cracked her head and was in the hospital unit just before she came here. They said she had had several fits and fallen. She'd had mild fits before without injury and it's awful but I didn't know whether to believe the consultant. I could never be sure they told me the truth. Then she had another fit here and fell, and I

felt terrible for having doubted them.

She had matured at the hospital but she is far more amenable now. She just ignored you before, you couldn't get her to do the things she does now. Margaret has learned to live in the community again. She couldn't learn that at the hospital. Even when they took her out, it was at least twenty in a coach. She was just one in a large group who couldn't be involved.

Margaret went into the hospital when one of her younger sisters was being born. It was just for six weeks. The consultant said that he hoped she wasn't as bad as I had described her because they might not be able to cope. She didn't want to come out. You see, I think that Margaret had to compete with lots of sisters. She knew she was different and didn't want to have to compete. She wanted to go back to the hospital when we brought her home again. She was very upset when we got back home — but, of course, that could have been because we had moved house. That is one way in which she is completely different now since coming here. She will now accept changes in routine, unpredictability. Before she had rituals. You had to do things the same way, go by the same route, go to the same places; she wouldn't go anywhere else. If you changed it would set her off, screaming and tantrumming. At the hospital when I visited, we always went to the café to the same table for a drink. We even had to drive the car the same way. One time when we passed my sister's home instead of calling in, Margaret went mad.

When she was nine, Margaret was said to be autistic. We took the Country Life magazine. Margaret used to collect them, a big pile of them. She liked to open each one at the page with the picture of the society lady and lay them down all over the floor of the living room and up the hall. Margaret would then walk around the magazines looking down at them hitting her chin with her knuckles. It was innocent enough but very strange, hard to explain when visitors came to call, so I tried to stop it. You couldn't tell her not to do it or take the magazines away, she would scream and tantrum. I gradually reduced the pile of magazines without her noticing. She did the same thing with the pattern on the carpet, walking round and round looking at it and tapping herself. Then there were the tin lids and mirrors. She got the shaving-type mirrors, the small ones which stand up by themselves, and liked to line them up in front of her when having a meal, watching herself eating. The mirrors used to get broken, swept off the table. I bought practically every mirror they had in Woolworths. I went on to give her tin lids in

which to see her reflection instead. She carried them about with her — the noise when she walked!

Margaret carried other things, a rag doll which she had at home and all the time she was at hospital, and still had when she came here. It wasn't really encouraged here, staff said they didn't really like it and thought she should be more adult and more constructively occupied. They got her a handbag to carry. Having younger sisters, when she comes to our home, she has access to dolls. She used to pick those up and carry them around but I would take them from her when it was time to return here and say that they stayed at my house. She can accept things now, I could take them from her without her screaming. The last time she was home, she wasn't even bothered to pick the dolls up to carry round. She carted things about at the hospital all of the time, they couldn't get her to do things instead.

Margaret can now do lots of things she couldn't before. She can make a cup of tea when she comes to our home. She is far more helpful about the house; still very speedy in the way she does things, but helpful. At first, after she had learnt things by being involved here, she wanted to do all the new activities when she came home. She's not so bothered now, but I think that's natural; I have other daughters who have changed like that. But she helps clear up the mess her sisters leave around. I say to them, 'Come on, tidy up, Margaret's coming home and if you don't she'll do it for you'. She helps me put clothes on the line. Her table manners have improved, that is a great thing. She used to eat so fast. They've taught her to slow down in Summerton Road. To do that takes effort every mealtime.

I take Margaret to Mass. All the family go, it is quite possible; marvellous really. She takes Communion. Margaret loves singing and has a lovely voice. If it is a hymn she knows she sings it beautifully. In others, she may sing something rather different. She loves the Christmas carol concert. But if it is a carol that just the choir are to sing, she doesn't sing. She watches me and if I don't sing nor does she.

There is no comparison between her life then and now. One thing I have come to realise is that Margaret is severely mentally handicapped. I'm not sure that I knew before. I just thought of her as wild. At the hospital they learned to control her in some way. She first went to what they called the rumpus room and then to the school. But her social behaviour did not conform to social

standards. It does now. I can take her to a café or pub. We do, we go out as a family together. I even went to the theatre one evening and found Margaret sitting in the row in front of me. It was such a surprise. I had never dreamt it possible; they would never have attempted it at the hospital; not as a single person anyway, maybe in a large group with some special dispensation for their behaviour. She was marvellous. She was aware that I was there after about ten minutes but she behaved perfectly all right. The quality of Margaret's life has improved out of all recognition. Anyone would want to lead it as it is now, but no-one would want to be stuck away in the hospital. Although they try hard, it's the system. She has such a full, busy life. One day she was at home with us having lunch and the 'phone went. It was the staff here to ask whether Margaret could come back soon as she was going to the Horse of the Year Show — wonderful, but they did it.

I didn't say this at the time, and I've never told Sandy since, but when it was first suggested that Margaret could come to live here I thought the proposal was a fairy story. I thought, no-one will cope — only one member of staff on duty at night! But then I thought that they only had two at the hospital to thirty-six patients and I realised it was much better here. Margaret was just one of thirty-six patients before — they were patients there, not clients of a service. She just sat, sat all day and rocked. Rocked backwards and forwards, that was her life. There was the odd outing. We took her out. We knew she was bathed specially because we were coming. But she still smelt terribly; you can't get rid of the smell of ages by one short bath. We would drive with the car windows open. I smoked then and would smoke twice as many cigarettes to cover the smell. Her skin is several shades lighter now, being free from the ingrained dirt. Margaret got fat in the hospital. It affected her walking. First she had to have a calliper on her leg and then it was looking like she'd need a wheelchair. She couldn't walk far and needed manhandling to get upstairs. They did realise at the hospital and slimmed her down, but stairs and distances were always a problem. Here she walks up stairs and she can take long walks now. I have to struggle to keep up. Her physical health has improved considerably. The whole atmosphere in the house is better, an atmosphere of a full and busy life. Before she had the existence of a cabbage. I am not saying they didn't try at the hospital but it was pretty hopeless. For example, the way Margaret swallowed food so fast was because if you didn't eat quickly someone else pinched it. I have seen it while

being there during teatime. A hand would come over and the food would be gone.

People here are treated with human dignity. You can't get that with open baths and loos, and we all need it don't we? The dormitory in the hospital wasn't entirely open. There were screens to separate the beds. I bought Margaret a bedspread to try and give her a personal corner in the ward. We are a big family and the clothes and presents we took Margaret in the hospital amounted to a lot. Virtually every time anyone visited something would be taken in. But there was nothing left, it was all gone, all disappeared. She came here with just two carrier bags of new clothes, obviously bought for her by the hospital for the occasion because the labels were still on. Nothing we had taken in had survived. Even the gifts from the previous Christmas had gone (Margaret moved in April). But Margaret herself is tidy. She looks after her things. Everything in her room here is kept just so. She tidies up at home better than her untidy sisters. In hospital she didn't have her own clothes. They just took anybody's. She even had someone else's shoes on once when we visited and she often came out in other people's clothes. I kept taking in good clothes and would get absolutely distraught because she never appeared in them. I kept her coat at home to make sure she had one that was decent when we went out or when she came home. They had clothes sometimes for special occasions, long party frocks, but not the daily necessities. Generally, Margaret would have no bra, or the wrong bra, or the wrong-sized bra. There was open nudity. You could arrive and people might be naked in the doorway, allowed to walk about naked.

Her elder sisters always understood about her handicap but her younger ones didn't know her. They and her father upset her on visits to the hospital so they didn't go. He's rather gentle and there is a special affection between them, so it was very difficult. Anyway for the younger ones, a visit to the hospital was a nervous ordeal. Now we have a different outlook. They see her at least once a week. Her little sister is really good, very natural in the way she talks to Margaret. They come here and we all go to church together. They can come in here on their own with Margaret. If we are turning the car round, they run on ahead. Her teenage sister is very proud when the girls from the school say they have seen her grown-up sister in town and remark, 'Isn't she pretty?'. Because she is, her appearance has altered totally. She used to have that dreadful long straight hair that she constantly chewed. Look at her now, it's styled. Her clothes

are picked just for her, specially to suit her, modern and to fit her. When she was a child at home Margaret always looked good. At the hospital it was impossible, terrible, and now she is here it is good again. The school at the hospital tried to make a stand about people coming presentably dressed. They would refuse to have them in school like that. But they had to give up in the end. They had their own clothes at the school to change people into while they were there.

Margaret now has a community life. I was in Safeways the other day and first I met one of my daughters who is in college in Manchester and had stopped off to do some shopping before coming home, and then I met Margaret. We had a quick chat and then parted. She didn't throw a tantrum, she behaved normally. She is living life like other people. You see when she was in hospital she missed her elder sister's wedding. Had she been here, she could have gone to the wedding and to the reception. She comes home for Christmas Day. That only happened once when she was in hospital; we tried the first time, but not again.

I don't feel this is a hospital. It is just a friendly place, a good atmosphere, everyone's nice to each other. One of the most remarkable things is I never felt it was all programmed. I didn't realise until recently that it's carefully structured. It seems just a friendly, ordinary household — really marvellous.”

Elizabeth Shaw: averting death and rebuilding a life

The central issue concerning Elizabeth Shaw's involvement with 10 Summerton Road was literally one of life or death. Elizabeth, a middle-aged woman with Down's syndrome, had been living locally in the family home. Her father had died some time earlier and, out of a large number of children, Elizabeth and two single brothers remained at home; with their now elderly mother looking after them and the household. Some eight years previously, Elizabeth had attended the local authority adult training centre but had refused to continue there following a minor road accident in which her transport was involved on the way to the centre one morning. Following her refusal to attend the day service, Elizabeth had become more or less “lost” to the services as a whole, receiving only occasional, uncoordinated contact. During this time Elizabeth became profoundly withdrawn so that

by the time service involvement became more concerted she was in a serious situation.

A year before the opening of 10 Summerton Road Elizabeth's family practitioner, prompted by concern from the social services department to begin to plan Elizabeth's future care, wrote to the consultant psychiatrist at the large mental handicap hospital in the neighbouring health district which still served the Merton area. Mrs. Shaw was approaching her mid-seventies and Elizabeth's brothers and sisters had been frank enough to admit that they were not going to accept the responsibility of caring for Elizabeth should their mother become unable to do so. There was professional concern to avoid a sudden crisis admission to residential care that such an eventuality would cause. The psychiatrist was asked whether periods of short-term care could be arranged to allow mother and daughter to adjust to being apart. Mrs. Shaw was deeply attached to Elizabeth, and devoted to caring for her. She would not hear of Elizabeth leaving home. It seemed that she felt like many parents of people with mental handicaps: believing that only she could adequately care for her child and experiencing such a strong sense of mutual interdependence that she almost wished that the death of her child would coincide with or precede her own demise. Moreover, Elizabeth herself was utterly resistant to any idea of leaving home.

Elizabeth was assessed by the psychiatrist as being in a "psychotic state" and, although short-term places were available, he judged that "an injection of Largactil" would be required to get Elizabeth to leave the house. It would be doubtful, therefore, if such treatment could be judged as being entered into voluntarily. He replied in this way to the family practitioner and the matter was left there. The situation was not known to health district staff involved in planning the new local service at the time. However, in the next two years a number of changes occurred: 10 Summerton Road opened, the family practitioner and the psychiatrist changed, and Elizabeth herself continued to regress and become increasingly withdrawn. There was a delay in the services picking up and responding to Elizabeth's situation; she was on the margin of service awareness.

Some time after 10 Summerton Road opened, and about fifteen months before Elizabeth's eventual admission, the new psychiatrist and the person-in-charge of the house visited Mrs. Shaw to describe the short-term care service of the house and to

offer Elizabeth the opportunity to make use of it. Although shy and reticent, Elizabeth was still healthy and, indeed, was slightly plump. Again, service staff were concerned that neither Elizabeth nor the family was in receipt of support and, in view of Mrs. Shaw's age, the home situation was vulnerable. Mrs. Shaw again made it clear that she had no interest in service involvement. Staff felt that Elizabeth was getting little help or support, that she was regressing, and that she was cut off from the outside world. The family practitioner, social worker, and a newly-established community mental handicap nurse were all involved over the next twelve months in trying to arrest a deteriorating situation. Individual programme planning was considered to be the best course to take.

At this time Elizabeth was practically confined to the house. The family as a whole had little social contact and what little Elizabeth had, in the form of a weekly visit with her mother to a neighbour's house, ceased when that neighbour died. Elizabeth had not been into town in eight years. Now it was a matter of whether she could be induced to leave the house at all. Objectives set in the first individual programme planning meeting between the community psychologist, the community mental handicap nurse, the person-in-charge of 10 Summerton Road, Mrs. Shaw, and the social worker — that Elizabeth should accompany her mother to the local newsagents' and the Post Office — were not accomplished. There was no real mechanism for programming such behaviour change. However, at least Elizabeth had been incorporated in some formal system of review and her mother, by attendance, had recognised some form of service involvement.

Rather than becoming more sociable Elizabeth withdrew further, spending most of her time in bed and getting up only to go to the toilet and sometimes to collect the newspaper or letters from the front door mat. This continued over a period of five months. Elizabeth did not even get up for meals and she began consistently to refuse to take food. Her mood became very agitated and changeable. The psychiatrist diagnosed "depression with psychotic overtones" and prescribed 25 mg of Melleril, twice a day. Elizabeth became increasingly thinner and frail, hardly eating or talking. When she did speak it was in a barely audible murmur. The family practitioner tried to be involved and did prescribe her some vitamins, but he had difficulty in gaining access to conduct a thorough physical examination. Elizabeth would not

tolerate it, kicking and screaming if approached. Despite considerable effort he managed only to take her pulse.

Elizabeth is intellectually more able than anyone else who has lived at 10 Summerton Road. She has the ability to comprehend what is said to her and to converse when she chooses. Before her illness she could manage most of her own self-care, dressing, grooming, washing, and toileting, needing some help with personal cleanliness in the latter. She was fully ambulant and had unaffected use of all limbs. She underwent such severe regression, however, that she barely did any of these things, and even became incontinent. Her body weight declined to just over four stones, at least two stones below an appropriate weight for her height. Apparently, Elizabeth had lost her adaptive functioning skills and had developed anorexia nervosa; undergoing a sustained and substantial weight loss, associated with refusal to take food. Later medical examination and investigation, accomplished upon admission to residential care, confirmed the absence of any identifiable physical basis for her loss of weight. She ceased to menstruate. As far as is known she did not have other anorexic symptoms, such as disordered feeding patterns, food hoarding, or regurgitation, but her refusal to eat was associated with other behavioural manifestations: profound regression, passivity, social withdrawal, and an agitated state. She also had a distorted sense of her own body image, evidenced by her saying she was "too fat". Certainly, this problem was felt to be sufficiently likely for care staff to avoid making reference to what she looked like in case it was detrimental. Such regression, including anorexic symptoms, is not unknown in the research literature; there is at least one other description of a middle-aged woman with Down's syndrome whose previous adaptive functioning and intellectual ability were much as Elizabeth's.

Whatever diagnostic label should or should not be applied, there was a grave danger that Elizabeth would die. She was very weak and susceptible to illness and the family practitioner had already prescribed courses of antibiotics. Her body weight continued to fall and attempts to coordinate an effective treatment programme within the family home, reliant on Elizabeth's mother as therapist, had not been successful. During this period, the senior staff from 10 Summerton Road had again been involved during the individual programme planning meetings and had arranged for Mrs. Shaw to visit the house so that she could gain a

first-hand impression of the service offered. Although she implied no criticism of the house, she had no interest in her daughter using it. She retained the dominant view that she alone could care for Elizabeth, others would not be able to manage, and, of course, Elizabeth was clearly demonstrating a lack of desire to leave her family home. The professionals involved were seriously concerned that Elizabeth was now in grave danger. Her sister had said that Mrs. Shaw did not discuss Elizabeth's care with the family, and she reiterated the family's unwillingness to care for Elizabeth if her mother were unable to continue to do so. The question of whether Elizabeth should be compulsorily admitted for treatment under Section 26 of the *Mental Health Act, 1983* had to be faced.

A special case conference was held in November, 1983. Mrs. Shaw was invited but did not come. Judgement was unanimous that Elizabeth required admission for appropriate treatment but views were divided as to whether urgency dictated compulsory admission then and there, or whether it could be delayed. It was proposed that the family practitioner and community nurse conduct a thorough medical examination and the nurse, social worker, and psychologist visit at least weekly to check the situation of mother and daughter. This demonstration of service determination seemed to have a rapid effect in changing Mrs. Shaw's position, albeit reluctantly, to one of acceptance that Elizabeth should be admitted for treatment to 10 Summerton Road. Within two weeks Elizabeth was admitted, not as a long-term resident, but for treatment only. The overwhelming priority was for the decline in weight to be halted and for Elizabeth to re-establish an appropriate body weight, strength, and level of activity. Another special meeting of the individual programme planning team was held within two months. This was partly to review the residential arrangements but was also prompted by some feeling of dissatisfaction in the way Elizabeth's admission had actually been accomplished.

In the end, events had moved quickly. Admission had taken place less than two weeks after a case conference which had effectively decided against immediate admission but for careful monitoring. There had been no improvement in weight despite her mother's attempts to offer food. The senior social worker, on receipt of the social worker's report, expressed real concern about Elizabeth's physical danger and he again raised the possibility of

admission under Section 26. The person-in-charge of 10 Summerton Road was on a week's leave but, on being telephoned at home, had gone into work and then to Mrs. Shaw's house. The psychologist and social worker were upstairs in the bedroom, attempting to encourage and induce Elizabeth to accompany them. Elizabeth was screaming and kicking and doing all in her power to resist. Mrs. Shaw, distraught in the kitchen, was saying, "Why don't you go on then: just take her; go on, take her". On entering this situation, the person-in-charge made a decision. He went upstairs, picked Elizabeth up and carried her, still kicking and screaming, to the car. With the psychologist as escort, he drove Elizabeth to 10 Summerton Road. The social worker stayed with Mrs. Shaw to do what she could to help her.

Elizabeth came to the house late one Friday afternoon. She was moved directly to a bedroom where she spent the remainder of the day. By the next day, staff had managed to get her up and had persuaded her to come down to the living room. This was a welcome success, for the staff shared considerable anxiety and concern that they lacked the skills necessary to care appropriately for Elizabeth. Again the key to their confidence and appropriate performance was careful programming by the senior staff with the aid of a psychologist, a doctor, and a system of detailed recording.

The individual programme plan initially had very basic objectives: to re-establish Elizabeth's intake firstly of fluids and then of food, and the gradual reintroduction of activity. Elizabeth was considerably dehydrated so fluid intake was the first priority. Her fluid and food intake, and whether she was in bed or downstairs, was monitored on a daily form divided into fifteen-minute intervals. The basis of the programme was:

Fluids

Elizabeth should have about three litres of fluid per day. This part of the programme is to encourage her to drink 200mls of fluid every hour, divided into four lots of 50mls, one for every 15 minutes. Each time Elizabeth finishes 50mls, record what the fluid was in the relevant time band on the recording sheet. If Elizabeth has not finished 50mls within an hour make sure she stays or comes downstairs and say to her that she has to drink so much fluid before she can go up to her bedroom. Show her a glass with 100mls and tell her she can go back upstairs after she has finished her drink.

If she takes a mouthful and then dribbles or spits it out, warn her that if she does it again you will put more in her glass. If she does repeat it, refill the glass by approximately the same as the amount wasted. You will need to keep her downstairs until she has drunk 100mls. This often means directing her to sit back in her chair after she has got up. Ignore the following behaviours (they often occur when she is downstairs for a drink or food): crying, slapping, kicking, hair pulling, shouting “no”. Reading her a page of a simple story after a mouthful or two helps.

Food

It is also important to encourage Elizabeth to take solids. These should be small amounts at regular intervals, at least two-hourly. Record type of food and amount taken. If food is offered unsuccessfully put X in the relevant hour square. See list of Elizabeth’s food preferences.

Activity

Elizabeth should get up for all meals and mid-morning drinks. Try to have her downstairs for one hour in every three, particularly during the day when some of the others are out. Encourage domestic involvement, particularly in the preparation of food.

On her first full day at 10 Summerton Road, Elizabeth drank nearly half a litre of fluid: orange squash and a high-calorie, concentrated glucose drink. She was out of bed and downstairs from 5.00 pm until bedtime at 10.30 pm. She took one taste of the evening meal. On the second day she took a similar amount of fluid, came down for a mid-morning drink, again at lunchtime, and then from 3.30 in the afternoon until she went to bed at 9.45 pm. She increased her intake of the high-calorie drink and took three dessert spoonfuls of oxtail soup. On the third day she walked downstairs herself for the first time, just after 9.00 am. She remained downstairs for the entire day, until 11.30 at night. She chose cornflakes for breakfast and had one spoonful, took a spoonful of beef broth and a bite of banana at lunchtime, seven-and-a-half teaspoonfuls of strawberry yoghurt mid-afternoon followed by a further two at teatime, and three bites of a cheese sandwich during the evening. This progress was maintained. On the fourth day, she ate twelve teaspoonfuls of porridge, ten

teaspoonfuls of strawberry yoghurt, seventy ml of beef soup, a square of chocolate, another seventy ml of beef soup, one small bar of chocolate, twelve teaspoonfuls of shepherd's pie, one slice of bread (half Marmite, half jam), and approximately four ounces of fruit cake during a day in which she was up and about from 8.30 am until 11.00 pm.

During Elizabeth's initial period in the house, the general practitioner who attended the household conducted a complete physical examination, including taking blood samples. The examination and subsequent investigations were sufficient to rule out obvious physical causes for the rapid weight loss. Progress in eating continued. Just nine days from the start of the dietary programme, Elizabeth was eating two Weetabix with milk and sugar for breakfast, four ounces of scrambled egg and fried potato and a cheese sandwich for lunch, and a quarter of a quiche lorraine with potato and beans for supper. Her fluid intake had risen to three-quarters of a litre. From the date of admission in mid-November until mid-December, the detailed daily records of food and fluid intake were maintained. By then Elizabeth was beginning to eat better and more consistently and a simpler record of food and fluid intake was adopted and kept until the middle of February.

Elizabeth's weight was monitored daily from the beginning of December until the end of the following July, and thereafter weekly. Her weight increased steadily during the first ten days but less quickly during the next fortnight. By Christmas Elizabeth was four stone twelve pounds (undressed), at least eight pounds heavier than her starting point of four stone four pounds (dressed). Her weight then declined again by four pounds over as many days. During January and February it increased again but fluctuated within the four to five stones range. A dietician's advice was taken in January. Her opinion was that a plateau effect on weight gain at such a stage was to be expected. The only deficiency she thought evident from her investigations was one of insufficient vitamin D, which could be rectified by Elizabeth going out of the house and being exposed to sunlight. From March to July Elizabeth's weight gradually increased to five stone five pounds; since then it has arisen above six stones. Special provision is still being made to ensure that she eats enough food but she now has a pattern of eating mainly at mealtimes like other people in the house. Indeed, the strategy of offering little but often was phased

out after good eating was established during the first December. Moreover, staff noticed that Elizabeth usually left something on her plate, however little she was given in the first place, so they began to offer her portions of a size that would be normal for a healthy appetite. The high-calorie glucose drink was only recently stopped but the main reason for its continuation was simply that Elizabeth liked it.

Having described Elizabeth's dietary programme and weight gain up to the present time, we have run on beyond the deliberations concerning the permanency of her stay in the house. The special meeting of the individual programme planning team held in the first December of her stay was attended by all relevant people, except Mrs. Shaw who was invited but did not come. The meeting discussed and recognised Elizabeth's weight gain and the behavioural change achieved during the preceding month but also acknowledged that further improvement was desirable. The social worker had talked to Mrs. Shaw about the need for Elizabeth to spend time away from the family home and reported that Mrs. Shaw was at least considering that Elizabeth might have repeated periodic stays in 10 Summerton Road. She still preferred this idea to the thought of Elizabeth living there permanently, however regular the visits home. But it was also noted that Elizabeth had not expressed a wish to go home or to leave 10 Summerton Road. Nor had she become distressed when her family left after visiting her.

Family members had held back from visiting while Elizabeth settled in. Mrs. Shaw came once in the first fortnight to satisfy herself that Elizabeth was adjusting well and was happy. Other members of the family visited subsequently and Elizabeth now has regular family involvement, a subject to which we will return. The December planning meeting was of the opinion that a long-term place in Summerton Road, with visits home, would be the most suitable arrangement for Elizabeth. With a view to this eventuality, it was decided that a place in the house should be reserved, tentatively, for her use. But it was premature to reach a firm decision until further discussion with Mrs. Shaw had taken place and more time had elapsed in which to gauge Elizabeth's reaction to living away from home. The planning team was also aware of the need to provide support for Mrs. Shaw. She was beginning to go out more than in the past; one week she had been shopping twice and had visited her daughter for coffee. The social

worker and community mental handicap nurse agreed to continue to visit her regularly. It was also recognised that Mrs. Shaw had found her visit to 10 Summerton Road stressful and so it was resolved that the person-in-charge should visit her at home to describe Elizabeth's progress and pattern of activity.

As Elizabeth was to stay at 10 Summerton Road, in the short-term at least, and as the immediate concern over her health and weight was receding, the area of programming and focus for change began to be expanded. Elizabeth had been admitted in a state of behavioural regression. She was doubly incontinent, having no control over her bowels and dribbling urine. She had lost self-care behaviours such as taking herself to the toilet. She tended to dribble at the mouth and wiping her mouth continuously was causing soreness. Her skin was dry and in poor condition. She had bad haemorrhoids. This, linked with a problem of constipation, meant that she was taking three different laxatives which probably did not assist her to remain continent.

Treatment of the haemorrhoids was started on admission and reinstatement of urinary continence was emphasised early on as part of the whole issue of Elizabeth being up and about more. By the December meeting, Elizabeth was reliably taking herself to the upstairs toilet from her bedroom and before bathing, but was more reluctant when downstairs. This was still leading to occasional incontinence which was one of the targets for continued change. A list of Elizabeth's preferred activities about the house had been drawn up and she was being encouraged to join in doing them as often as she liked. In early December, Elizabeth had been into the garden for a short time and had seemed to enjoy it. It was decided to encourage her to walk around the garden more and then to venture out as far as the local shops. It was also decided that she should work towards going home for a visit. If she did prove to be genuinely phobic about travelling by car, a programme would need to be designed. (A phobic reaction had been cited as the reason why Elizabeth had refused to go to the adult training centre following the slight accident in which she had been involved. That occasion had been the last time she had travelled in any form of transport before being taken from her home to 10 Summerton Road.)

Another conscious aspect of programming, once the immediate concern about weight loss had been remedied, was to give Elizabeth a positive view of herself. If Elizabeth had some form of

self-image, the aim was to enhance it; changing her view of herself as a dependant, helpless child to that of a responsible adult. At a very obvious level, she had few clothes that fitted her after losing so much weight. New clothes bought or provided by the family were adult in style. Her hair was styled and attention was given to her appearance, with the intention that she should feel attractive. At the same time it was felt she should assume a greater responsibility for the household tasks her life generated. From December she, like everyone else living in the house, started to be involved in the systems operated for planning activity generally and for acquiring specific teaching goals. A programme for staff, setting out how and when to respond to Elizabeth when she cried, was formalised. This included an emphasis on how to prevent Elizabeth using crying as a means of avoiding making a contribution to household life. At another level, the dryness in her skin referred to earlier was treated by adding baby oil to her bath water.

Elizabeth grew into living permanently at 10 Summerton Road. The individual programme planning meeting, held at its routine time three months after the special meeting called to review her admission, recognised the general change in the family view which had now fallen in line with the professional judgement expressed at the special meeting. Once the permanence of her stay was settled, her family began to take an active interest and staff began to meet members of Elizabeth's extensive family network. Many family members have brought her clothes; as a consequence she has a large wardrobe. Elizabeth goes to her mother's home every weekend, for tea one weekend and to stay overnight on alternate weekends. One of her brothers who still lives at home walks to 10 Summerton Road to collect her and they walk back together. A married sister living in Merton also sees Elizabeth regularly, about twice a week. She and Mrs. Shaw have attended all the individual programme planning meetings about Elizabeth since the two special meetings which discussed and reviewed her admission. They have come to accept and support the service involvement and they now both contribute to the content of the service programme.

Elizabeth's visits home started after she had been on her first successful shopping trip from 10 Summerton Road. That had taken place at the end of January, two months after coming to live at the house. A good deal of persuasion had been needed to get

Elizabeth to venture outside the house, but once out she had enjoyed herself. She had gone to the shops and had a drink in the café. She had even met her brother while out quite coincidentally (again indicating some of the advantages of a local service). It was a great occasion for them both; the first time Elizabeth had been in her local town centre for eight years. This outing was quickly followed by an appointment at the hairdresser's and a visit to a pub. Elizabeth even started to initiate outings. She still does not go out as frequently as some others in the house, but she now chooses whether to go out or not. Going out is not a problem. Elizabeth probably averages about two outings a week, other than those involving visiting relatives.

In the last year, Elizabeth has re-established her self-help skills and is participating more and more in domestic life and household shopping. She is a little more sociable and outgoing than before, though still shy and reticent. She has travelled in cars again. She is fully continent and basically fit and healthy. She has a good relationship with members of her immediate family who are supportive of the service and have a good relationship with service staff. Elizabeth's world is expanding again; she is provided with a service that is programming new experiences for her, is teaching her new skills, and is making sure that the simple, obvious things she needs are done (such as getting her eyesight tested). Establishing an alternative means of occupation during the working day is also part of the agenda — possibly re-attendance at the adult training centre, possibly outside employment. Elizabeth's attendance at review meetings as a member of her own individual programme planning team is also something for the not-too-distant future.

Kathleen Wright: leaving home but staying close

Once sufficient community services become available to provide appropriate and adequate coverage, people with mental handicaps who require residential care will be able to move from their family home to an alternative residence locally. This will avoid the dislocation of ties with friends, family, and locality which still characterises most mental handicap services to this day. The small home service at 10 Summerton Road serves a sector of Merton and its surrounding countryside which has been worked

out to provide a match between the number of places provided and the demand for residential care. It is designed to serve its catchment area comprehensively in terms of provision of intensively-staffed, residential accommodation for adults who are more severely and profoundly mentally handicapped. Now that the initial relocation of residents from distant institutions with kinship ties to the territory has been achieved, it is intended that in future the people admitted will have been resident locally in family households. The only exception to this policy is, as in the case of Margaret Tarrant, when the next-of-kin of an institutional resident moves to live within the catchment area. Thus, even though the initial emphasis of the community-based alternative service is in part deinstitutionalisation, once that is achieved the function of the service becomes almost entirely one of serving local community citizens, much in the same way as a school serves local children. The role of the service in relation to Kathleen Wright illustrates this.

During the first two years that 10 Summerton Road was open, Kath lived at home with her mother and father and then, following the death of her father, with her mother alone. Her parents were both retired and Kath herself was in her mid-forties. Her three brothers and her sister had all left home, although one brother returned to stay at weekends. Kath herself attended the local adult training centre five days a week. Apart from this, and an evening at the local Gateway Club once a fortnight, she had little occupation outside the home.

Kath is a shy, anxious person, who is without physical handicap or any obvious physical signs of mental handicap. She does, however, look older than her years and has a hunched-up posture and tentative movements. She is reticent, usually talking only when spoken to. She often withdraws from the activity of the adult training centre, preferring to stand alone near the workshop door. She also often cries for no apparent reason, either when alone or when answering apparently innocuous questions. She talks in sentences with appropriate grammatical structure, but her conversation shows little evidence of mature reasoning and is stylised and repetitive. She talks of herself as a child and in defensive vein, perhaps in imitation of what others have said about her: "I'm not a naughty girl, am I?"; "I'm not that handicapped, am I?". Thus, though her language may have some developed content it serves no developed, positive function. It does not, for

example, seem to provide her with a means of controlling her environment by making demands of others around her, or to help her gain an understanding of the world. Although her spoken language has elements of sophistication, Kath is poor at following instructions and is as slow to learn as the other people we have described in this book. She needs a great deal of encouragement to do simple everyday things, let alone attempt to do anything new. She sometimes becomes very agitated when demands are made of her. Her anxiety, and even her speech, may serve a defensive function to deflect such demands. As a result her adaptive and intellectual skills appear underdeveloped. She is more handicapped than she seems; probably less able than she might have been had her abilities and confidence been nurtured and stretched.

In describing Kath's involvement with the service we would like to highlight three of its aspects which appear particularly relevant for her: the nearness of the residential service to her family home which enabled Kath to maintain other important parts of her life undisrupted; the development of adulthood in her personal appearance and in her role as a responsible contributing member of the household; and, the development of her confidence, assertiveness, and an improved self-perception.

Local proximity

Local residential services allow people who are likely to be future service users to come into contact with them before they actually need them. When the time comes for them to require full-time residence they also allow people to keep their existing personal and service ties intact after admission. Before moving to live at 10 Summerton Road on a permanent basis Kath had received periodic, regular, short-term stays. As a result of these stays she had got to know Carol quite well. When Carol obtained a place in the adult training centre which Kath attended the care staff set out deliberately to foster shared interests between them. Carol was interested in going to the cinema, concerts, and for evenings out generally. Kath had a fairly restricted social life. Therefore, long before Kath became a permanent member of the household, Carol and a member of staff would occasionally call for her and they would go out together. Carol and Kath now share a room together.

Living locally means that other relationships have been

maintained. Although the time Kath spends with her mother has declined since she has left home, they still see a lot of each other but the character of such contact has changed. A change has also occurred in Kath's relationship with her brother, sister-in-law, and two nieces. Kath stays with her mother for one weekend every fortnight. By doing so she keeps in contact with one of her brothers who also comes to stay at weekends. She sees her other brother and his family, who live locally, every week as Kath and her mother are both invited to dine with them on Wednesday evenings. This level of family involvement, together with the evenings out that Kath has with Carol and other people from the house, means that Kath has a very full social life. Out of personal choice she has continued going to the Gateway Club, held every other Monday evening; another example of existing ties and relationships being maintained by virtue of the local nature of the residential service. In addition, Kath has retained her place at the local adult training centre during the day and the ties she has there. The length of time one may be on the waiting list for such a facility has been well illustrated in the accounts of the people who have returned to the locality from distant institutions. The situation is analogous for someone who has to move out of the area served by a day-care service that is already being provided in order to receive a residential service.

Unfortunately Mrs. Wright was presented with a less than free decision concerning her choice about whether Kath should continue to live at home with her or should move to 10 Summerton Road. From its inception, 10 Summerton Road had offered a short-term care service. This was generally not frequently used but had been taken up on a regular basis by one or two families, including Kath's. Kath began by having one week-end stay per month. Her family wanted her to live at the house permanently when the time came, but did not want it to be yet. The service agreed to keep them informed on the occupancy of the house. Before his death, Kath's father expressed a wish for her to continue to live in the family home. Mrs. Wright wanted to fulfil this wish, but at the same time she wanted Kath to stay at 10 Summerton Road more regularly. Kath began to stay from Friday to Tuesday alternate weeks. Shortly afterwards, as part of the council's improvement programme to the housing stock, Mrs. Wright was temporarily rehoused and arrangements were made for Kath to stay full-time in Summerton Road during this period.

However, pressure for a decision on admission now came from the health authority's finance department.

10 Summerton Road had never been conceived of as part of a deinstitutionalisation programme, but as a means of providing a community service. On the rationale that it could not be expected that the intentions of people with severe and profound mental handicaps and their relatives, in demanding use of a residential service, would fall conveniently in line with an authority's decision to provide one, it was envisaged that full occupancy of the house would take a matter of some months or years to achieve. Such a rationale was stronger among those providing the service, who were closest to the needs of service users and their families, than among the treasurers of the authority, but a certain tolerance of under-occupancy was created over the first two years. The house had been approaching full occupancy when Richard and Mary had unexpectedly died. Although the extent of occupancy does not affect the total revenue expenditure, it does inflate the revenue costs per person to a level which begins to be described as excessive. Moreover, the auditors wondered why the authority was proposing to provide further facilities elsewhere while existing services had "spare capacity". Mrs. Wright was told of the pressures coming from the bureaucratic centre to move to full occupancy and was warned that if she wanted to ensure Kath had a place she should accept it while it was available. After consideration, this is what she chose to do, although her decision can hardly be represented as a free and unconstrained choice.

Having made the adjustment to Kath living at 10 Summerton Road, Mrs. Wright is very supportive of the service. She regularly attends the individual programme planning meetings for her daughter and has expressed a desire to become more involved in the house generally and in the lives of the other people living in it. For example, she has suggested that Carol might come with Kath to stay at the week-end and she gave Carol a present for her last birthday. Thus, from the viewpoint of both Kath and her mother, the establishment of this local service can be seen to protect people's ties to the past, recognise their current interests, and set the foundations for new networks of relationships to grow in the future. Perhaps one of the most graphic illustrations of how having a local service can allow people with mental handicaps to keep important personal ties is that Kath can still visit and lay flowers on her father's grave.

Assumption of adulthood and the development of confidence and self-esteem

When we first knew Kath, we saw her as someone who was very shy and nervous, like a submissive child who would reply when spoken to but would otherwise sit or stand apart from the mainstream of activity around her. After living at 10 Summerton Road for a little under two years she retains these essential characteristics, but to a lesser degree. Certainly one conscious line of effort has been to bring Kath out of herself, to shift her own, and her family's, perception away from one of her as a child, to increase her participation in life around her, and to encourage her to make choices and yet be more carefree.

The relatively easy part of achieving such a prescription concerns the more obvious symbols of adulthood and status: her appearance, and the way she is approached and talked to by other people. In her mid-forties, Kath physically looked older than her years, but other aspects of her appearance were child-like such as having flat-heeled shoes and long, straight hair gathered at the back. Her mother was not at first amenable to Kath having her hair cut and styled but was eventually convinced by the argument that her hairstyle was difficult for Kath to manage herself. It took considerable staff time to comb it every day and prevent it tangling, just as it had taken similar amounts of her mother's time previously. With a mature, well-groomed hairstyle, smart high-heeled shoes, and new clothing in the style of a smart, middle-aged woman, Kath is less easy to treat as a child. She can read a few words (a small social-sight vocabulary) and she now has a pair of reading glasses. A hearing loss, not previously identified, means that she now has a hearing aid. In themselves, such devices are not particularly exceptional. However, not having them contributes further to a person's functional handicap. If correctly chosen the type and style of spectacles or aid can be strongly symbolic of age and status.

The way people who are not handicapped talk to those who are is amenable to change. It does not involve changing the behaviour of the person who is handicapped but that of other people in contact with that person. It is part of the ethos of the house that everyone who lives there is treated politely. This involves treating people in an adult way, viewing them as being capable of making informed choices, and with reciprocity or equality in social dealings. For example, if staff want people living in the house to

come with them when they want them to do something, then those people ought to have the same ability to get staff to accompany them when required. If staff wish members of the household to look on them as friends, and be on first name terms with them, then first name terms should be reciprocated. In addition, examples of friendship can be offered by staff outside of work. When first coming to live at the house, Kath was submissive and juvenile in her dealings with most adults. In her family she was treated as a child, to the extent that even her young nieces (eight to ten years old) were explicitly given a supervisory role in relation to her. Outside her family, she dealt with adults as a school child would; she called everyone "Sir" or "Miss" according to their sex. She defended herself against criticism or demand by weeping. This characterised, and to a large extent still characterises, her behaviour at the adult training centre. In the house, however, staff have consistently encouraged her to use Christian names and to make demands. If she wants something, she is encouraged to ask for it; to express her wants, such as a simple desire for a cup of tea. If she wants social attention she is encouraged to approach others in order to gain it, rather than sitting or standing in a weepy or agitated state until someone asks, "What's wrong?"

Some success has been achieved in changing Kath's behaviour. Crying has declined. She will sometimes ask for things; and she is beginning to make simple choices and express preferences, such as between different breakfast cereals. She has been brought more into the household activity, as an equal participant, pulling her weight. She has learned to do many domestic activities which she had no opportunity to do before. Since she has practised them at 10 Summerton Road she is able to do them in the family home when visiting her mother; an example not only of the generalisation of learning from one situation to another but of the changed family perceptions of Kath. Family members have responded partly to the example set by staff in the house, partly to Kath's changed appearance and behaviour, and partly because of the progress they have seen in other people living at Summerton Road. They now treat Kath in a much more grown-up way. Kath's sister-in-law recently worked as a volunteer, escorting Shirley to and from work. She was struck by the incongruity of her inclination to hold Shirley's arm or hand — Shirley being mentally handicapped, deaf, and partially sighted — while escorting her along the pavement, knowing that she has mastered a job of paid

work. She realised that there were obvious parallels to be drawn in thinking about how to treat Kath.

The fact that Kath has left home has generated for her family the feeling that she is now an independent person, much more effectively than would ever have been achieved by our simply having taught her independence skills. Kath's family now talk about her as an independent person. Her nieces are now less frequently in the situation of looking after Kath and they talk to her much more as an aunt these days.

Socially, Kath likes many things, but as a spectator rather than as a participant. She likes and goes regularly to the cinema, pubs, a local folk club, and concerts, as well as to watch events at the sports centre. As she grows in confidence and independence there is no reason why the horizons of her life should not continue to expand.