

CHAPTER 4

Mary M . . . — family contact is not the only consideration

The wisdom of moving people with mental handicaps who are in, or are approaching, old age and who have been accustomed to institutional life for many decades is one issue that those developing alternative services are certain to encounter. Although barely middle-aged, the fact that Shirley had spent thirty-five years in a large hospital led her father and sisters to be uncertain which choice to make in her best interests. The same issue arose with respect to Mary, a woman aged fifty-three, who had been in residential care for over forty years.

A second issue is that of moving people from an institutional setting to a local service some distance away. Most people can see the sense of this if family members live nearby who are keen to continue or resume active contact. But what if they have lost, or have deliberately withdrawn, contact for many years? Should someone who is mentally handicapped be left in an adverse situation simply because of lack of interest on the part of the family? In Mary's case this second issue was also present, and in a form for which we were less than well-prepared; namely, an extreme conflict between her mother's opposition to the suggested move and what we saw as being in Mary's best interests.

The relevance of these two issues in terms of Mary's experience of moving to an ordinary house in the community is sharpened by the fact that, eighteen months after her transfer, she died. Compared with the four decades she had spent in two institutions, eighteen months is a short time; but, as our account should show, the effort in striving for improved care for people who may only experience it for a relatively short time is not wasted.

When 10 Summerton Road was being planned, Mary was resident in one of England's three special security hospitals for mentally abnormal offenders. She had not been found guilty of a crime by the courts but had been transferred there because of disruptive and aggressive behaviour in the mental handicap hospital where she had lived previously. She was detained under the sixth schedule of the *Mental Health Act, 1959*, by an order which was renewed every two years until 1980. Mary was eligible

for a place in the house because her mother, now elderly and widowed, lived in its catchment area and because the house sought to serve all adults with severe or profound mental handicaps whose lack of functional ability merited the intensity of staffing provided. After initial contact was made, it was clear to us that Mary had been effectively abandoned by her family.

In describing the situation in such objective terms we do not wish to engender a lack of sympathy towards Mary's family. Her mother, Mrs. M., often acting on advice, had done what she thought was best, not only for herself and other members of her family, but also for Mary. It was a situation to which she had become adjusted, though it had caused her emotional difficulty throughout her life. The unexpected contact from staff of the local service was another source of disturbance. Our approach came as a considerable shock and it was immediately obvious on visiting her home to discuss the opportunity for Mary to transfer to 10 Summerton Road that the proposal caused her serious distress. She had experienced difficulty in sleeping since she had received the letter from the consultant psychiatrist requesting the visit. She had seen her general practitioner for medication because of her state of anxiety, and she spoke openly of a possible breakdown if the matter were to continue or if Mary were to be moved to the locality. She maintained the view that, if the purpose of our visit was to obtain her permission to such a move, she categorically refused to give it.

On discussing the issue with Mrs. M. we were both sympathetic to her and concerned for her state of health. We did not want the tranquility of her life in old age to be overturned. On the other hand, we recognised our responsibility as representatives of Mary's welfare. We also recognised a wider responsibility; that of encouraging local services to accept individuals who were no longer appropriately placed in the special hospitals. We felt that the plight of the special hospitals and their residents would remain unaltered if local service authorities showed no resolve in finding alternative placements for those who were fit to leave.

We soon realised that Mrs. M. had few people to turn to for personal support in this unforeseen difficulty. Only one member of her immediate family even knew of Mary's existence, and she was unwilling for him to be approached or involved in the discussions. She also refused to disclose the name of her doctor in order that the psychiatrist could professionally consult her medical

advisor. The conflict of interest between the welfare of the mother and that of the daughter seemed irreconcilable; even to the extent that continuing the discussion could be viewed as an unjustifiable intrusion likely to be seriously detrimental to the mother's mental state.

From the little information gained from our one meeting, it seemed that the crux of the problem involved two factors. One was the social embarrassment that would arise for the family, and the mother in particular, should it become known that there was a family member with a mental handicap whose existence had been denied. The other was the prediction that, if Mary moved to the locality, it would not be possible to keep her identity concealed. Mary's family was well-to-do. Her mother was sure that her distinctive surname would soon be associated with her family if it became known locally. She was concerned about the reaction of the rest of the family, her friends and neighbours, and the local press if the situation came to light. She could not see why her grandchildren should be forced to come to terms with the discovery that they had an aunt who was "peculiar and severely handicapped".

Mary had been admitted to a mental handicap hospital near London as a child. During the Second World War, there was a period in which Mrs. M. did not see her, which resulted in a deterioration in their relationship. Mrs. M. had then been advised by her own general practitioner and the staff of the mental handicap hospital to make a complete break, in the best interests of both Mary and herself. The hospital staff asked her not to visit, as Mary became disturbed afterwards. Subsequently, Mrs. M. had been kept informed by the relevant authority of Mary's place of care and any serious episodes in her life, such as the illness that had brought her close to dying. She sent money for staff to buy Mary Christmas presents. She had adjusted to not seeing Mary any more and did not wish to face further change so late in life.

Understandably, Mrs. M. viewed Mary as a woman who was severely mentally handicapped and behaviourally difficult, who had developed little in her fifty years, and had posed such extreme problems of management that it had been necessary to transfer her from one mental handicap hospital to another, and then finally to a state security hospital. She had become totally dependent on service authorities for knowledge of her daughter; and this was the impression that they conveyed.

Although Mrs. M. appreciated the sincerity and good intentions behind our representations, and although she was aware of concerns over the quality of care provided in the state security hospital in which Mary was living in particular, and in large institutions in general, it must have seemed to her insane to suggest that Mary could move to live in an ordinary residential road in the middle of her local town and be managed successfully. She saw her daughter being the centre of a public disturbance, followed by inevitable press coverage.

Of the limited information Mrs. M. had received about Mary in her rare dealings with the services, much was to do with difficulties. She knew, for example, that Mary banged her head against the wall in temper, and that she attacked others. If Mary moved Mrs. M. would have to make a terrible decision: whether to re-establish contact with her or not. She was probably sure in her own mind that she would not. This would be difficult though for, if she continued to shop in the local town, she would have to pass 10 Summerton Road knowing it was where her daughter lived; in a repeated act of ignoring her existence rather than the current, more passive denial. She also wondered whether she would recognise Mary should there be a chance meeting in town.

We were faced with many questions. Who was the client of the service? What rights did parents of adults with mental handicaps and the adults themselves have respectively? Who should represent the welfare of an adult who, because of mental handicap and language deficiency, could not make a reasonable, informed choice? How should a decision to take a course of action in support of one individual's welfare be weighed if there was a possibility that it would be seriously damaging to another's? Mary's mother talked not only of nervous breakdown but also of taking an overdose to end her life. But the moral dilemma was transitive: failure to take a course of action to benefit one individual, in order to protect the interests of another, presented an equally unsatisfactory conclusion.

In our deliberations, the following factors seemed relevant. Firstly, the initial opinion that Mary would be likely to benefit from the transfer remained unchanged. The route out of the difficulty should not be found by adjusting our assessment of the extent of benefit Mary might be predicted to gain from the transfer. Establishing greater family contact through providing local services is only one of a number of possible benefits. Even

with no contact from her family, the increased opportunities available to Mary within the type of care planned were seen as having considerable potential to benefit other aspects of her life. Therefore, if she were not transferred simply as a result of parental opposition, the service could be guilty of implicitly judging her welfare as being of secondary importance.

Secondly, there needed to be some judgement of the likely consequences for both parties. This was the central issue. Although difficult it had to be faced. There was no doubt about the level of Mrs. M.'s distress; but there was at least a possibility that this might be alleviated by the passage of time and with the aid of those who were close to her. If Mary was not transferred to her local service authority, it was fairly certain that she would remain in hospital for the rest of her life. Exactly how damaging that would be to her was unknown. Certainly she would never be aware herself of a missed opportunity for improvement but such a consideration did not materially change the fact that, in not acting on her behalf, we would be condemning her to spend the rest of her days with a quality of life lower than it might otherwise have been.

Thirdly, it appeared relevant to consider the normal parent/adult child relationship. In considering this issue most of us had experienced acting, as adults, in opposition to our parents' wishes and, therefore, we took the view that parents are not necessarily unbiased representatives of their children's welfare. We could not simply concede our responsibility to Mary by considering her mother's view paramount. We agreed, as a matter of principle, that the parents of an adult with a mental handicap had the right to be informed of matters concerning that adult but not the right to give or withhold permission in that regard.

Lastly, there were some bureaucratic policy considerations. We felt that our local service should support the reduction in size of the special hospitals but could envisage many forms of opposition to the placing of people from special hospitals in the community. We felt, however, that if local services did not act with some determination to accept former residents of the special hospitals the size of those institutions would remain unchanged. We also felt that, within the National Health Service generally, there was an active principle that although people had a right to treatment, the professionals involved retained some discretion on the place and nature of the service.

These last considerations may be considered as the insensitive hand of bureaucracy. But returning to Mary's mother's position, the fatalism which she expressed of the bureaucracy doing as it had intended irrespective of her wishes was the only sign that she had at least countenanced the possibility that Mary would indeed move to Summerton Road. The person-in-charge of the new house visited Mrs. M. again, alone this time, after he had been to see Mary and the circumstances of her care in the special hospital. He had two aims: to describe the philosophy of the proposed service, the opportunities it offered Mary, and the safeguards that would be built into the model by the high level of staffing and day-to-day structure; and, secondly, to discuss ways in which the service might act to overcome her fear of disclosure of identity and subsequent public notoriety. Any option was worth considering, even that of Mary adopting a different surname. The person-in-charge gave a guarantee of complete confidentiality on the part of the service. He also guaranteed that no further contact with the family would ever be made by the service. In fact, if she chose, Mrs. M. need never know whether Mary had moved or not.

After his second visit, Mary's mother wrote to the person-in-charge. This letter influenced the views of the members of the case conference which considered and recommended Mary's transfer, one phrase being seen as giving tacit agreement to the transfer subject to the two guarantees. Staff at Summerton Road were never informed of Mary's family background and were instructed never to use her surname in conversation with any outside party. This was in line with the general requirement not to talk about the concerns of any person living at the house except to other service staff. The guarantee of no contact was kept until it was necessary to inform the family that Mary was seriously ill with an inoperable brain tumour.

A second letter from Mary's mother enclosed a Christmas present. She was thanked and informed that it had been put to good use. The complete absence of further contact meant we were unable to discover just how much distress Mrs. M. suffered as a result of Mary's transfer, so a complete assessment of the wisdom of the decision can never be reached.

Mary: before moving

Mary moved to 10 Summerton Road in the second week of November, from an environment which had aspects of prison

security, such as being confined to a locked dormitory from early evening until morning. Her contact with the outside world was non-existent and her behaviour, the cause of her transfer to the special hospital, was disruptive. She displayed temper tantrums at least two or three times a week. These were sometimes so intense that she fell to the floor and forcibly removed her clothing. She also damaged property, pummelling surfaces with her fists and breaking windows. She had attacked staff over a long period but these outbursts, as well as the more extreme forms of self-injury she had once shown, had declined. Her disruptiveness, therefore, should perhaps not be overstated. She was living on a pre-discharge ward and her move was considered appropriate by the professionals involved in her care.

Mary had a severe mental handicap and few self-help skills. She ate using a spoon and her fingers, could drink unassisted but with considerable spilling, and could dress (given that she wore loose tops and elasticated trousers) with help. She was fully ambulant but with a lop-sided gait. She was generally continent but did not wash even her hands herself. On the *Fairview Self-help Scale* in 1976 she obtained a score of 31.4 months. Reassessed in 1978, she scored only 19.9 months. Whether she had regressed or whether scales of this kind are prone to such variability is open to debate. The ward staff gave no indication of anything other than Mary being in a fairly stable state. After the move, she was assessed again, scoring a mental age of 28 months.

Mary was extremely sociable, to the point of inappropriateness. She would greet even total strangers in an intimate way, putting her arms round them in a bearhug and kissing them. She would physically hold on to people and not let go. Such actions were accompanied by very limited and repetitive speech. She was physically affectionate to people sitting next to her and would grasp their forearms or rub their backs and say, "I like you, I like you . . .". Her entire vocabulary comprised a few phrases and a number of odd words which she used in delayed, echolalic fashion. She could identify a few objects but could not distinguish between the sexes or follow simple instructions. Her personal possessions were gathered constantly around her in bags and on her person. She was said to hoard rubbish up her sleeves and to become frustrated when thwarted, showing temper by stamping her feet, slamming doors, and throwing herself to the floor screaming. She also collected and hoarded books and had no appreciation of other

people's property. She was described as being jealous of attention shown to others. Although very sociable when it suited her she could sometimes be withdrawn, often choosing to sit or lie on the floor, inactive, away from others. She was seen as stubborn and persistent in her idleness; attempts to direct her into an activity group were frequently met with temper tantrums.

Mary's appearance on arrival at the house was not flattering to her. She had thick black hair which had only a rudimentary style and lacked lustre. Her face showed signs of damage (she was reported as rubbing and picking it, causing sores and injury). She had a few disordered teeth and no dentures. She had little clothing: some underwear, a few round-necked pullovers and trousers with elasticated tops, an anorak, and a pair of shoes which, although new, were about two sizes too big. Her personal belongings were two large and worn teddy bears and some well-thumbed fashion catalogues. She took them with her wherever she went and thumbed through the catalogues repetitively.

Strategies for change: what can be done immediately?

As in other accounts told here, the kind of health care, quality of clothing, and attention to personal appearance which people with very severe or profound mental handicaps receive is dependent on other people's activity on their behalf. Their resulting health and appearance should not be seen as a function of the extent of their handicap but rather of the care or neglect of the service. These areas have the potential for immediate change. Progress does not require greater personal competence on the part of the person who is handicapped, something which is a genuinely slow business to achieve. It does require that the objective to improve aspects of the person's health and appearance be specified and that staff seek for and safeguard quality in these respects. It also requires that staff numbers are sufficient to allow time to be spent achieving and maintaining progress. Numbers and time in themselves, however, are not enough. It is also necessary to set standards for achievement, and these need to be taken from the non-handicapped world.

The importance of presentable appearance is manifest in the attention it receives in today's world; in advertising and in the amount of money spent on fashion, clothing, and hairstyling. In thinking about whether these are important to people with severe mental handicaps a number of considerations are relevant. Firstly

there is self-image: will the person appreciate his or her own appearance? We think so on the whole but we do not always know. We are sure, however, that it is important to assume that someone with even the most severe mental handicap can be aware of interpersonal differences and can take pride in looking good. This is an assumption which protects quality; adopting the opposite viewpoint can only lead to the possibility of neglect. Secondly, personal appearance affects the perception others have of a person. Poor appearance seems to be unpleasant to other people and generates avoidance. If someone has a behavioural handicap which also produces this response it is important to avoid compounding the problem. As we have mentioned before, audiences find it difficult to believe that the people we illustrate in talks about 10 Summerton Road really have severe and profound mental handicaps. They associate good appearance with greater ability and better functioning. Thirdly, in a service which sets community integration as one of its goals, good appearance is part of a reasonable bargain with the community-at-large. Social integration involves acceptance; and this can be helped or hindered by appearance as well as by behavioural characteristics. An emphasis on presentable appearance lessens the extent to which it is necessary to appeal for a special attitude to be shown by the community to its members with mental handicaps.

In the first six months after moving to Summerton Road, Mary received an extra share of the clothing budget in order to purchase a suitable range to her wardrobe — a new top coat, dresses, and shoes. As well as looking right, it was found that more fashionable, adult ladies' shoes with a slight heel helped her to walk with a more normal gait. She went to the hairdresser and the chiropodist, and began a course of dental treatment leading to the provision of dentures. She was proud of her new appearance. She liked having her hair done and enjoyed brushing it herself. Apart from a slight awkwardness in movement, in time Mary's appearance gave little indication of her handicap.

It is important to emphasise that in distinguishing the issues of ability and appearance, and in highlighting the separate importance of appearance, the presence of a real, functional handicap is not being denied. It is true that an individual's behavioural deficiencies or problems can make the task of attending to appearance more difficult. For example, when Mary received her dentures she had difficulty in wearing them without

gagging. This might have been due to the dentures not fitting properly, which in turn could have been due to the difficulty of obtaining an adequate impression. Mary was not able to help the dentist as other people might. There was also the question of teaching her to wear them; getting her used to having teeth after many years of being without any. Thus in order to attend to this aspect of her appearance, staff had to embark on a long-term programme of structuring increasingly longer occasions when Mary would wear her dentures. If they were successful in achieving even short but significant usage, the dentist was willing to put further effort into obtaining a more precise moulding that would fit Mary more closely.

This example illustrates the complexity of coordination and effort that may be required to obtain personal characteristics for individuals with handicaps which accord with the broad range of standards for other people. There is an interaction between seeking high quality involvement from the various branches of the helping professions and developing individuals' behaviour appropriate to the activities involved in maintaining such standards, achieving personal care, or using materials to good effect. However, in relation to people with severe and profound mental handicaps, learning can neither be achieved quickly nor on a broad front simultaneously. It is, therefore, necessary to be wise in making decisions as to what to teach. The targets chosen need to be important to the life of the individual.

It is also necessary to consider when to teach. A teaching strategy for wearing dentures was unavoidable, given that nobody could help Mary by wearing her dentures for her. However, an alternative strategy to teaching is often possible in which staff help to bridge the gap between personal accomplishment of the individual and what is required. In many ways staff can act as a prosthetic device. Just as spectacles bridge the gap between the current ability of an individual's eyes and the visual acuity needed, staff act as a social prosthesis helping the person who is handicapped to behave as others do in similar environmental circumstances. The analogy with spectacles also helps to give an image of the extent of help to be given. In just the same way as an overly strong prescription for glasses will lead to a deterioration in the muscles of the eye and an increasing dependence and worsening of sight, excessive staff help leads to overdependence and often overprotection. Staff must give the minimal help

required and allow the person to contribute personally as much as possible. As in the other stories in this book, direct involvement in household life following this strategy of staff support had a direct and major impact on Mary's life style. Into this fitted the more selective construction of teaching programmes.

Behavioural development

Early priorities for teaching were concerned with improving Mary's mode of eating, her table manners, and her ability to wash and to dress, and gaining her cooperation in joining in the activities of the house and getting more appropriate social interaction. The temper tantrums and screaming described in hospital Mary probably displayed in order to avoid demands, to avoid becoming involved, and to keep herself to herself. For example, it was found that she particularly disliked washing her hands, and the cracks in the plaster above the handbasin in the kitchen at Summerton Road still bear testimony to her displeasure at being requested to do so for herself. Mary generally needed coaxing to carry out any domestic assignments. If already sitting down she would often say "No, no, no" to any request to do something. Therefore, in order to preserve the normal social convention of asking her whether she would like to do something, rather than telling her, while at the same time keeping to the objective to promote Mary's meaningful occupation, staff learned to ask her to get up and come with them, suggesting the intended activity to her a few seconds after she had stood up.

As Mary became used to joining in more and learning simple domestic tasks, such as emptying the dishwasher or pegging out the washing, her agreement to follow requests became easier to obtain. Once occupied, she participated with good grace, enjoying the social situation. However, care had to be taken not to let one task be merged into a second or third; a common strategy which attempts to translate agreement to one request into another rather than facing the situation of seeking agreement to a new request. Mary liked to celebrate her achievement by saying, "I done it", and then returning to the living room to sit down. Care had to be taken to allow her the opportunity to be pleased at having done what she had been asked to do before asking something else of her. The breaks between activities did not have to be prolonged.

In this way, there were relatively few occasions on which there was major conflict between Mary's will and that of staff. The

destructive behaviours and serious temper tantrums displayed in hospital were encountered relatively infrequently. Early on, she broke a few windows and there was a more protracted problem concerning handwashing. This was the subject of a specific structured programme, organised on similar lines to the more general approach which staff were beginning to learn was the most appropriate mode of interaction. Mary used to scream and hit the wall above the washbasin. Staff responded to her outbursts consistently by saying “No” sternly and turning away from her. Once the tantrum had stopped, they repeated the request while at the same time guiding her to be successful.

There is some research literature that has looked at systematically varying the level of difficulty of demands made of people with mental handicaps who display inappropriate behaviour in order to avoid situations. Demands for simple tasks which an individual is capable of doing may be met with compliance while requests for more complicated activities, which may still appear exceedingly simple to staff, may generate disturbed behaviour. Experience with Mary seemed to fit well with such an analysis. She was extremely sociable, enjoyed praise, and articulated accomplishment. At the same time she had been considered in her previous environments to be stubborn and difficult to occupy in activities, other than those she chose for herself which were almost always lacking in adaptive function. As she became more competent, however, she became more ready to participate though staff had to remain sensitive to her real understanding of language and avoid increasing the difficulty of their demands beyond her level of development.

During the year following her transfer, Mary had a thorough, progressive review of her medication. On arrival, she was being prescribed 200mg Epilim twice a day, 5mg Valium morning and night, and 10ml chloral hydrate at night. She was also written up for 100mg Largactil by intra-muscular injection when needed. The chloral hydrate and Largactil were immediately stopped. With a longer waking day and progress toward a new sleeping pattern it was predicted, correctly, that Mary would sleep without need of medication. And it was not intended that any behavioural disturbance would be treated by sedation. The Valium was reduced shortly afterwards. Meanwhile the psychiatrist wrote to the special hospital to find out whether the Epilim had been prescribed as a result of a history of epilepsy or as a response to

Mary's behavioural disturbance. The reply indicated that epilepsy had never been apparent, so the Epilim too was gradually reduced once the administration of Valium had been phased out entirely. By the end of 1982, Mary was receiving no medication at all and the psychiatrist's notes record improving behaviour alongside drug reduction.

Her physical ability was also reviewed. Although having the use of all four limbs Mary was found to be restricted in movement on one side. The local physiotherapist was consulted, who was able to design about ten arm and hand exercises to strengthen her weak side. Mary worked on these with the aid of the staff of the house.

The new opportunities that were available to Mary within the general context of staff support led to fairly rapid development. She quickly learned to use a knife and fork at mealtimes. She was so thrilled with this new accomplishment at first that for a few weeks she chose to eat everything by that means, even her toast and marmalade at breakfast. In hospital she had been described as taking food from others' plates and being terribly messy, but now she learned to wait for others to finish before taking more, to offer serving dishes (when prompted) to others, and to use language to express preferences and wants. Her proficiency at eating unaided improved enormously.

She also participated in the routine domestic tasks of the house: clearing the dining table and putting the things on the kitchen hatch, wiping surfaces, sweeping or vacuuming the floors, cleaning her own room and helping with the communal ones, dusting ornaments, doing the washing, hanging clothes out, taking them in, ironing, putting clothes in the airing cupboard, and removing them from there to the wardrobe and drawers in her room. She went shopping almost daily. It is true that the majority of these things were done with staff instruction and direct guidance, but through regular practice and some specific teaching Mary increased considerably the part she played and the level of independence she displayed. For example, she became gradually more competent at aligning and positioning different types of crockery and cutlery in the dishwasher so that in time she could load it herself when asked. She could also empty it and put the crockery and cutlery away in cupboards and drawers.

Specifically programmed teaching taught Mary many whole and component skills for her personal care and household life. She was taught to wash her hands using soap; and then to dry them. Once

she had learnt this the tantrums that she had thrown when asked to wash her hands died out. Having learned this successfully she was taught to wash her face using soap and flannel, and to dry her face, neck, arms, front, and groin after bathing. She learned to look in a mirror while brushing her hair, first for three seconds, then for five, and then for seven seconds. She became able to unscrew and remove the cap from the toothpaste tube and to clean her teeth on both sides. She learned to put clothes on a hanger and hang them in her wardrobe, to put folded items neatly in drawers, and to look for and take out required items without totally disturbing the remaining contents. Mary was accustomed to undressing by pulling off all garments worn above the waist together, and all those worn below the waist together. This damaged her clothing and also meant that it needed to be unravelled before she could redress. So Mary was taught to take items off singly. By careful structuring of natural opportunities Mary learned to collect the dirty washing from people's rooms and bring it to the laundry room, and to wash small items of clothing by hand. She placed objects in cupboards or on surfaces on request, that is, she developed an understanding of the prepositions "in" and "on". She learned to drink without spilling, to put a half-full milk jug in the fridge without spilling, to fetch, empty, and return the office wastepaper bin, to take full bags from the kitchen bin and put them in the outdoor dustbin, to hold a dustpan for someone else to sweep into, to sweep garden leaves into a pile, to vacuum the carpet, to tip liquid left in cups down the sink before upturning them in the dishwasher, to wash up (alongside another person), to dry saucepans, to fill teacups to the correct level from jug or teapot (first with and then without a verbal instruction), and to take a pillow case off a pillow.

Other changes important to Mary's development occurred in relation to her language and socialisation, both in the house and outside. Mary had an extremely sociable personality which should have been reviewed as an asset but her pattern of social interaction was so odd that her sociability had been cast as an inappropriate trait. Her repetitive speech was extremely wearing and the way she approached and greeted people could be off-putting, particularly to the unaware. She physically grasped and held on to people and was generally over-intimate. As someone who had moved back to the locality from placement far afield, there was no immediate prospect of Mary receiving any day-care service. Her

life style was one of a middle-aged housewife who could shop daily for bread, meat, and fresh vegetables if she so chose. Having previously lived under prison security, Mary's experience of this side of life had been greatly restricted. Going to shops and having a meal in a restaurant or a drink in a pub represented significant new opportunities for her. If she were to gain the best possible benefit from her new environment and avoid the kind of negative reaction which her mother had predicted, it was an urgent matter for Mary to be taught more appropriate social skills.

At first, Mary greeted all visitors to the house, people returning to the house, and even people inside the house in an inappropriate manner. In order to teach her to keep an appropriate distance and to offer her hand to shake instead, every physical contact Mary initiated in an overly-intimate way was met by an impassive correction. This comprised releasing her grasp, moving back slightly, taking her right hand to an offering position, taking her hand and shaking it, and at that point smiling and saying the normal social pleasantries. This was rapidly successful in shaping her interactions with people within or coming to the house. A similar effort was made when Mary reached for and held people while shopping, such as a cashier or sales assistant. She was physically corrected and verbally reprimanded. Mary had a particular tendency to address staff in supermarket overalls as "nurse"; understandable, given the limitations of her experience over many years. This too was discouraged. Her improved appearance, now smart and presentable, may well have counted for little if her mode of interaction had not changed. Gradually, however, she learned to offer her hand in greeting rather than to embrace people, and to distinguish between people she knew and those who were strangers.

Another factor that was detrimental to Mary's image and her ability to participate effectively in the domestic round was a habit of carrying her possessions around with her, particularly two large and worn teddy bears. Although these were never taken outside the house, early on they went everywhere with her inside. In the same way that Shirley's doll's pram had considerable potential for projecting a continuing juvenile impression, irrespective of other changes which might be made, so too had the battered teddies. However, unlike Shirley's pram the phenomenon did not correct itself by virtue of the other opportunities in the house. A positive approach had to be followed in an attempt to supplant their role in

Mary's life by acquiring other, more age-appropriate accessories which she would prefer to keep with her. Mary was encouraged to purchase a handbag. Given the interest shown in it by the people round her and the opportunity it gave her to be similar to adult women in her immediate surroundings, Mary began to choose to take this with her instead of the teddies. The handbag also served as a repository for other items Mary treasured — a number of handkerchiefs, combs, and some small picture books. In time, she was taught to put her handbag down when in the house and to collect it when going out or moving to sit in another room. Moreover, as her personal property increased, her tendency to hoard items reduced. The teddies, at first kept in her bedroom, were eventually discarded.

Community living, recreational pursuits, and social life

Mary had many chances to go shopping and to visit cafés and pubs for refreshment. She was able to push the trolley in a supermarket and to collect goods from shelves with instruction. She learned to wait for change when making purchases, and to buy herself a Coke in a café. Her sociability led to many genuine social exchanges as she became a familiar and regular customer in the locality. She had a tendency to show people she did not know very well what she had bought, such as when she purchased some new earrings. This still marked her out as being socially immature for her age; but it was a far more preferable and appealing peculiarity than her earlier means of contacting people.

One story can illustrate how well Mary was accepted within the community. She had become a regular shopper at a local bakery. One day, when the shop was particularly crowded, Mary and a member of staff entered the baker's and waited at the back of the queue. Totally on the assistant's initiation, Mary was asked to help serve behind the counter. The assistant said something like, "Come on Mary, come and help — we are busy . . . This lady wants six bread rolls in this bag here". Between the shop assistant and Mary, the lady was served. When Mary later became terminally ill, many people asked after her. Although she knew no-one when she came to the locality, some thirty people attended her funeral (the combined staff and resident group at that time was only seventeen).

Within the house, Mary contributed fully to the household routine. More than any of the others she also organised her own

leisure activities. She liked to look at books and to do simple interlocking jigsaws, an accomplishment she brought with her from hospital. She continued these activities, choosing to get out jigsaws or books from the cupboard when not otherwise busy in the house. When she needed something to work on she collected one of a nest of tables and placed it by an armchair in the living room. Although the activities themselves were not new, there was some development in the way Mary pursued them. When she first moved to the house Mary gave every impression of being someone who had lived in an environment in which personal belongings were not respected: in hospital she had gathered all her possessions to her person in a number of carrier bags and kept them with her wherever she went. When first in the house she had carried the teddy bears with her. When they were replaced with the handbag she carried that with her just as much to begin with, using it to collect and keep small possessions. As time went by Mary was taught to reduce the number of items she carried around with her and to keep her belongings in the cupboards available in the living room and her own bedroom. She gradually learned that, in this house, other people would not interfere with her personal belongings. The small, childish books she had brought with her were replaced by more adult books, these retaining a similar emphasis on pictures; for example, books on nature, gardening, and travel. These were too large to fit into a lady's handbag and had to be kept on the shelves in the living room. Her puzzles and other recreational materials were kept in the cupboard above the books. Therefore, although Mary continued the kind of recreational pursuits she had followed in hospital, her new home environment provided a different and more preferable context for such activities. Leisure became an activity of choice, fitted in between personal and domestic chores, which Mary organised for herself. She learned to undertake the more extended sequence of arranging her environment: getting a table out, getting the materials from the cupboard, and putting everything away afterwards. She could at last rely on the fact that it was possible to have personal belongings within a group setting which would be safe if she left them unattended.

Mary was also interested in watching television and she liked listening to music. She learned how to turn the television on and off to gain greater independence in this respect. She shared these interests with Carol (see next chapter) who had a stereo and a

television set in her own room. Mary was often invited by Carol to watch television with her in Carol's room — a special form of companionship. Mary began to arrange and keep a photograph album which she liked to look through periodically. With modern cameras, photography is a simple hobby that can be enjoyed by people with severe mental handicaps. Unfortunately, its expense is a considerable barrier and serves to illustrate the personal poverty of most people with such handicaps in our society.

In the time after moving to Summerton Road Mary went to the cinema a number of times, went to music concerts, attended church, visited a riding stables and attended a gymkhana, went on all-day shopping excursions to neighbouring cities, ate lunch and dinner out in restaurants, visited the homes of staff, used public transport, and played pub skittles. Many of these events occurred in the evening. Mary kept the hours of an adult; a distinct difference to her life in hospital. Holidays were another new form of activity. In the one summer that followed her move to the house, Mary had spent a holiday with Shirley and two members of staff in a caravan at a seaside resort. The caravan park had a restaurant, bar, and entertainment complex which they used as adults.

At the onset of Mary's illness, further avenues for recreation were being explored. These would have involved her in more extended community contact. One possibility was horse-riding, which would have been started through Riding for the Disabled and subsequently continued independently. Another was regular attendance at lunchtime concerts at the local college of further education.

Mary had no family contact as explained earlier. She did build up a personal friendship with a few local citizens, something that staff tried to encourage due to her particular circumstances. Apart from the relatives of other people living in the house four people visited Mary. Two developed a particular friendship with her. The shop assistant who had invited Mary to serve bread rolls in the baker's shop became a regular visitor. Her fiancé (later her husband) also became involved. They visited Mary at the house and also did other things which friends generally do, such as when meeting her in town unexpectedly, deciding to go off together to a café for a coffee. Mary was able to entertain them at home, offering them coffee (with staff help) or inviting them to stay for a meal. Staff fostered the friendship and began to talk to the couple

about whether they would be prepared to act as external advocates for Mary's welfare at her six-monthly individual programme planning review meetings. They had agreed to do so and would have attended the next meeting in that capacity if Mary's illness had not intervened. Mary was invited to and attended their wedding.

Mary appeared to be extremely happy in her new life. Staff took a consistent approach to her tantrums and the behaviours that were damaging to property. Their decline, however, may equally well be attributable to the generally more stimulating environment, Mary's own increasing capability, and the direct experience of the results of her contribution to household life. A structured approach to changing Mary's initial tendency towards non-compliance into a likelihood of cooperation was important in maximising her development and the use of the opportunities available to her. Care always had to be exercised in inviting Mary to engage in household activity; without it she could easily refuse.

In a world of greater activity, greater material enrichment including personal possessions and a range of clothing, more opportunity to go shopping for food, household requirements, and personal belongings (toiletries, cosmetics, tissues, and jewellery), and increased social contact, Mary's vocabulary increased by leaps and bounds. This development was aided by her echolalic capacity to copy speech. Learning what objects were called was not difficult for her; she had a well-established tendency to imitate other people. In order for her speech to develop some functional meaning, all that was required was the consistent creation of situations in which she needed to use language in order to obtain the outcome she wanted. Her sociability gave her a strong desire to gain other people's interest in and approval for what she was doing. It is very likely that her developing language helped her sustain her sociable world.

Mary's use of language however always remained repetitive in character and on a bad day could still be wearing. It was typical for her to show someone a personal possession, such as a new pair of slippers, saying "slippers", "new", "pretty". This would be repeated, not only several times in a single episode but from one day to the next, until they could hardly be regarded as new. Her considerably expanded vocabulary did have the benefit of diluting the particular nature of her repetitive speech and allowing a much greater pool of possible utterances and subjects to be discussed.

More to the point, although Mary's language retained its repetitious character, not all of her expression was echolalic. She was able to answer questions and state preferences or choices without repeating herself.

Serious illness

It was around the time of Mary's second Christmas in the house that staff first began to observe worrying signs. She appeared a little frail at times — showing a slight stumble, a lack of balance, or a failure to stand up from the armchair at first attempt. She also started to become slightly less cooperative again. She had always had a minor physical disability causing weakness on one side and staff were well aware of her tendency to refuse requests, so neither problem was new. Her increased non-compliance was also a matter of only a slight change in degree. It was nothing like the level of refusal to join in which had characterised her early days in the house. Even so, staff were sensitive to these changes and raised them for discussion at the weekly staff meeting. Two courses of action were agreed. One was for staff to be especially careful about the difficulty of the requests they made of Mary and the length of participation they expected of her. In other words, the procedures which had worked in establishing her greater participation in the first place were reinstated. The other was to consult Mary's general practitioner and psychiatrist for medical examination and opinion. Early in the onset of her illness, later diagnosed as a brain tumour, medical examination did not detect any untoward clinical signs and the psychiatric advice did not add to the management strategy already adopted. Therefore, no specific action arose from this line of inquiry.

Over the next two months, the signs which had first alerted staff that something was wrong accelerated and Mary started to hit her head and pull out her hair. Even if staff could contemplate Mary going to such lengths to be left alone (which they found difficult to accept), the form of disruptive behaviour chosen struck them as incongruous. In the past, her opposition had taken a different form — temper tantrums involving screaming and hitting floor, table, or wall with her fists — so why had she not returned to these rather than adopting a different behaviour? Mary had also become particularly proud of her appearance, especially of her hair. Staff therefore suspected that she was experiencing pain and again asked for a medical opinion. This led eventually to a full

neurological examination, but not before Mary had pulled out most of her hair. The effect on staff, on Mary's friends, and on everyone else who knew her was extremely upsetting. None of them was able to accelerate the processes which might gain Mary respite from her suffering, which had now become all too evident. Staff had shown sensitivity in their identification and interpretation of the early behavioural signs of growing distress. They then experienced delay in gaining appropriate examination and medical referral.

Mary was admitted to the neurological unit of the nearest teaching hospital. There, a rapidly-growing and inoperable brain tumour was diagnosed. Mary was given medication to relieve the pressure within her head which, in expert opinion, must have caused her considerable pain. She remained an inpatient for about a week, the medication successfully controlling pain as judged by the cessation of hair-pulling. As there was no curative treatment possible she was deemed ready to return home.

The fact that Mary returned to her home at 10 Summerton Road, and was cared for there during the last stages of her terminal illness, is relevant to the current debate over the ability of ordinary community settings to cater for specialist problems. Arguments in favour of community care should not be interpreted as being incompatible with special arrangements being made for people when necessary. There is a considerable emphasis within the principle of normalisation on catering for individual need by the most powerful and intense strategies available. A competent service would be expected to make specialist (different) arrangements specific to each individual's requirements. But in doing so, it should also seek to keep unaltered all other arrangements that are important to an individual which are not in need of change. Thus, when Mary's conspicuous need was for neurological examination she received it, as other citizens would, in the normal specialist way which involved a temporary stay away from home. However, once the need for accurate assessment, diagnosis, and decision-making concerning treatment had been met, new requirements became paramount.

The service responded by allowing her to pass her last days in comfort, in familiar surroundings, and among the people she knew best. Mary, therefore, returned to Summerton Road where arrangements had been made to ensure her comfort and care. She moved to a bedroom on the ground floor, where a hospital bed was

installed to make lifting and turning easier (the easier it was for staff, the more comfortable it would be for Mary), and discussions were held with the community nursing service so that they could be called upon if necessary. The two senior staff at the house were trained nurses but they were not specialists in caring for a dying person. However, their experience helped them to teach the other staff how to give Mary food and drink, how to care for her skin, and how to lift her into and out of a bath. The community nursing service gave specialist advice but did not supply direct labour. It had been envisaged that they might make domiciliary visits to help with bathing and toileting and with turning at night. However, when Mary became so frail that house staff were concerned that she would suffer undue discomfort from being handled by just one person, they devised a rota of sleeping-over duties so that day-staff could provide the additional pair of hands required. This initiative was supported by senior management who provided appropriate additional payment.

With these arrangements for her comfort and nursing care, Mary was still able to have what benefits she could appreciate from home life. Other people living in the house, on returning from their day-care settings, often went to Mary's room to see how she was. At least two showed visible concern. Afternoon tea was taken together in Mary's room and she was visited frequently by friends. Her care was beyond reproach, a credit to the staff. She died in June 1983.

A final consideration

Mary had lived for forty years in specialist institutions providing residential care for people with mental handicaps. She had spent a quarter of a century in her last place of residence, a state security hospital. No doubt she was accustomed to the life. The decision that she should be moved to 10 Summerton Road was complicated by more than the usual number of doubts which often attend such new ventures. These mainly concerned her family. But in addition Mary was detained under a Section of the *Mental Health Act, 1959* and this required that official DHSS sanction had to be given to her transfer. (The Section was eventually lifted, not to be renewed, some seven months before her death.) Although it is not unusual for people to move from security hospitals while their Sections are still in force, and such official restrictions are not automatically proof of extreme difficulty in personal behaviour, it

is much less common for them to move directly to a small community setting.

Had Mary been older, say in her late sixties rather than her early fifties, the proposition that she was accustomed to institutional life, that it was “too late”, and that it would therefore be personally detrimental to move her might have been made with some force. It is never quite clear whether the area of concern in such arguments is based on the individual’s limited life expectancy and the view that such temporary disruption to the individual is not justified, or on the assumption that, at a certain age, making any form of change becomes too difficult. From our experience of a number of people with mental handicaps who have moved to new homes on various occasions, we think that the extent of the disruption can be overstated. This may be particularly true for people with more severe handicaps who, because of their relative lack of skills, may have established few strong interpersonal ties. Mary, unexpectedly, only lived under changed circumstances for a short time, a little over eighteen months. Clearly some balance needs to be drawn; but no-one who was involved with her after the move doubted the wisdom of it or the benefit she experienced from her new life up to the onset of illness.

Traditionally, provision of residential care for people with mental handicaps, inherited from our predecessors, has been in the form of large institutions. We do not wish in any way to question the concern of the staff in these institutions for the welfare and the care of their charges. Nonetheless, there has been a growing movement towards a policy of building appropriate services to care for people within the community. The onus of proof is still on the care in the community developments to demonstrate that individuals do benefit from a life in a community setting as opposed to one in the traditional form of provision. Those familiar with the means by which the benefits of a service arrangement are often judged in relation to people with mental handicaps, will recognise the emphasis given to developmental progress and the growth of skills. Such developments essentially reverse the defining condition; the absence of capability and the slowness in learning which is called mental handicap.

This account of Mary has described behavioural development, how she grew in independence. But at the end, that growth in skill comes to nought, reversed first by illness and then by death. What is left as having perhaps been more significant to Mary in her life is

the actual character of life in the house, something which is more difficult to describe and needs more detail to capture: the routine round of her daily experience, the opportunities for participation and contribution, the increased breadth of experience, and the purposeful nature of the involvement she had with her material and social world. It seems to matter very little that before she became ill she had become marginally more skilled than before. The importance of that development was in how it contributed to the way she led her life from day to day. She was still an impossible distance away from ever becoming an independent adult. The benefit of the change is that she lived in an environment which supported the best use of the capabilities she possessed and enabled her to maximise her own contribution, allowing her access to some of the good things of life. Without claiming that the quality of service in the house was perfect, it is possible to claim that through its philosophy there were aspects of life style and opportunity afforded to Mary which most people would consider preferable to those available to her in her previous circumstances. The measure of benefit is that she experienced these for 592 days.