CHAPTER 3

Catherine Henderson — avoiding institutional care

Catherine Henderson arrived at 10 Summerton Road on the same day as Shirley White, three weeks before her twenty-second birthday. Unlike Shirley, she came from her family home nearby and was already known to the local neighbourhood. She has a profound mental handicap, with very limited ability and, on arrival, seemingly little inclination to respond to the requests of others. Her parents were in quite desperate straits: Catherine wandered constantly and could not be controlled verbally. Their entire day was geared to coping with her as best they could, a task which was placing a considerable strain on them.

We first met Catherine's parents at a meeting for members of a local voluntary society whom we consulted regularly over the provision of the house. Discussions were often difficult; society members wanting to have some control over who was to be admitted and disagreeing strongly with our view of an arbitrary admission policy based on catchment area. Quite understandably from their point of view, the wish that Catherine should be guaranteed one of the first available places was one objective behind the lengthy discussion of the issue. From our viewpoint, however, the service needed a responsible policy to ensure equal opportunity for any eligible person with a mental handicap. The debate on principle was never actually resolved.

In the event, Catherine gained a place at 10 Summerton Road by virtue of her residence in its designated catchment area. She and her family were clearly in need of a high quality, competent service. Discussions gave us a vivid insight into the family situation, the strains being experienced, and the grave possibility of imminent breakdown. As will become clear, Catherine's behaviour posed constant problems of management, and she had few redeeming skills to provide balance between stress and hard work on the one hand and enjoyment on the other.

Catherine, unlike many people with similar behavioural and intellectual characteristics, was not already in residential care because her parents had fought against her placement in an institution. That was the last thing they wanted for their daughter.

They had accepted short-term placements in the two nearest large mental handicap hospitals but had been distressed about her condition on her return home. During her last short-term placement Catherine had been transferred to the locked ward where Shirley had lived. Pressure on her parents meant that they had to accept whatever short-term respite was offered but they were aided in their resolve not to accept long-term care in an institution by the views and support of some of the prominent members of the local voluntary society. These members counselled against accepting long-term institutional admission and actively campaigned for community-based alternatives to be developed. They had raised the capital required for a local hostel which had been given to the social services department some three years earlier. It was a considerable disappointment to Catherine's parents that people as severely handicapped as their daughter could not be considered for admission there. They continued to care for Catherine as best they could, whilst hoping for further local developments and an improvement in the quality of residential services.

The opening of 10 Summerton Road was, therefore, what Catherine's parents had always hoped and waited for. They had no doubt that they wanted Catherine to leave home when the house was ready. Although she had a place in the special care unit of the local adult training centre, the break provided to her parents was insufficient to alleviate the strain. Catherine was supposed to arrive after the others and be collected earlier, staying between 10.00 am and 3.15 pm approximately. Her mother used to try to delay the time she arrived to pick her up in the afternoon as much as possible. From then on it was home, tea, an attempt at containment, and off to bed in the early evening. Of course an adult cannot sleep for more than twelve hours every night and so Catherine learned to rise early — anything from 5.00 am onwards. At least one of her parents had to get up and stay with her, often resorting to driving her around in the car as a means of occupation and distraction until the time permitted for her to arrive at the training centre.

Catherine, having a profound handicap, had very few positive skills and little means of occupying her time. She had a few poorly articulated words, mainly the names of people and foods. She was ambulant, overweight, and wandered with a rocking gait. She pestered for food, would help herself to it, and would not stop

when told "no". She ate very noisily, using a spoon and fingers and leaning well over the table so that her mouth was close to the level of the plate. She did not help with dressing or washing, was doubly incontinent at night, and had accidents during the day. Some of these "accidents" may have been deliberate. Her most conspicious characteristic was persistent removal of her clothing. This had been a problem behaviour for many years. One of us had even been asked to advise staff in the special care unit about it (obviously unsuccessfully) some five years before.

When Catherine moved to 10 Summerton Road, she was in the habit of removing her clothing continuously throughout the day. Every attempt to get her clothes back on was met by almost immediate, if not simultaneous, undressing. Consequently, she spent as much as seven hours of her day in a state of partial or complete undress. There was no time during the day when it could be guaranteed that Catherine would not strip, irrespective of where she was. It was not unusual to walk into the room at the special care unit and find her naked, sitting on a chair with a blanket draped across her. The frustration felt by staff was made worse on occasions if, having managed to dress her completely, she then wet herself causing them to undress her again to wash her and change her clothes.

On coming to the house, Catherine's wardrobe comprised an outdoor coat, socks, pants, sandals, and a number of blue towelling one-piece catsuits which tied at the back with four bows. Catherine liked blue; it was the only colour she would allow people to dress her in. The one-piece suits were an attempt to discourage her from stripping. After a period of short-term care in one of the mental handicap hospitals, Catherine had been returned home in a nylon "strong-suit"; a sturdy, one-piece garment resistant to removal or destruction. This was seen as being too severe but it contained the germ of a good idea. Catherine's parents asked one of the members of staff of the special care unit to make up some equivalents from blue towelling. Unfortunately, these were not very helpful in controlling stripping because Catherine could remove them. Unlike nylon, the towelling could be pulled out of shape and the ties weakened. However, irrespective of this, the blue suits became an important element of Catherine's management strategy. Despite their unsightliness they were accepted as her only form of attire during the first few months at the house.

Catherine was very heavy, weighing about fourteen stones. Coupled with her poor gait, this meant that she could only walk a short distance by herself. She was in receipt of Mobility Allowance and she possessed a wheelchair which her parents had used when taking her shopping. The hair on her head was thin, she had more facial hair than usual for a young woman, and she drooled at the mouth, making an almost constant wet area on the front of her clothing. As with Shirley originally, the severity of Catherine's handicap was made noticeable to all, and even accentuated, by her appearance.

Initial management

Of the people who were moving to 10 Summerton Road in the first months, Catherine presented the most conspicuous and constant picture of difficulty. Her behaviour, though harmless, was highly detrimental, time-consuming, and inappropriate. She had a profound mental handicap, few self-help skills, virtually no form of constructive occupation, an inability to sit (except at mealtimes) for anything longer than literally a few seconds, and an absence of response to requests, even to the point of failing to give any indication that she was aware that she had been addressed. She took no notice of people when they initiated contact; and did not make eye-contact with them (that is, look at their eyes when they talked to her) even when they were directly in front of her. However, she was not in herself unsociable. She liked company, and if she had any wants she would approach people to make demands. Under these circumstances she established good eye-contact! But she had no interest in meeting the demands others might have of her. It was part of her lack of skill. Instead she wandered ceaselessly, performing a characteristic, ritual movement which involved holding her left arm up, one finger pointing forward, and rotating it in circular fashion in the left-hand side of her field of vision.

Apart from helping Catherine to settle into her new home, initial service effort followed three complementary strategies: a systematic programme of staff response to stripping, with a view to Catherine choosing to remain dressed throughout the day; staff concentration on finding a means of occupying Catherine more constructively to fill the time she spent wandering or stripping; and, provision of help to improve her physical appearance, including weight reduction, change to conventional clothing,

better hairstyling, and control of drooling.

The three priority areas were interrelated: a major loss of weight and an end to the use of the blue suits would require a completely new wardrobe. They needed to be done in concert because money for new clothes was limited. It was also thought that the transfer to conventional clothing should follow successful management of stripping; the first target for remaining dressed being for Catherine to keep on the blue suits. While proceeding with the weight reduction other ways of improving Catherine's appearance were sought, such as having her hair smartly cut and excessive facial hair removed. It was also important for staff to have a coherent approach to occupying her when up and dressed. A fairly crude initial appraisal was that the stripping acted as a non-verbal form of communication which solicited, and usually gained, staff attention. Reversal of the inclination to strip, therefore, depended firstly on Catherine discovering that she would lose staff attention through being naked and could only regain it by dressing. But secondly, and perhaps equally importantly in the longer term, it depended on Catherine gaining staff attention for doing other, more constructive, things. Thus, staff had to help her with constructive activities. As Catherine is profoundly mentally handicapped, staff help needed to be extensive. Given Catherine's slowness in learning, her participation in constructive activities could not wait for her to be taught new skills. The strategy had to be that she would be immediately involved in the activities of the house with whatever staff support was required to bridge the gap between her capabilities and the requirements of the task.

During the initial period after opening, only four people with mental handicaps lived in the house and although a full complement of staff had not been appointed, the staff:resident ratio was at its highest during this critical period. Catherine was almost constantly with a member of staff. The easy part of the strategy was the diet. A one thousand calories per day reducing diet was designed following consultation with a dietician. But the approach to stripping and to getting Catherine to participate in constructive activities were full-time, day-long endeavours.

The initial programme to reduce stripping was as follows. It was decided that Catherine could choose to be naked if she wished but, if she did so, she must obey the normal convention of decency and stay in the privacy of her own room. (She had a single bedroom

upstairs.) If she stripped elsewhere in the house, staff would take her and her clothes to her bedroom and wait outside for her on the landing. When she wanted to leave her room and rejoin the activities of the house, she would be given the opportunity to dress and helped to do so. If she did not dress she stayed in her room. When dressed, staff would re-engage Catherine in the life of the house, joining in ordinary household and self-care activities. To achieve this often called for complete physical guidance, a staff member's hands over Catherine's helping her to do the task. Moreover, an arm would often need to be around her waist to prevent her from wandering away. Also, at this stage Catherine did not always look at what she was doing which of course did not help her to make a positive contribution to the activity. There was, however, no obvious alternative to this strategy of maximum help if Catherine were ever to become engaged in useful activity for which she could gain considerable staff attention.

This approach to stripping was rapidly effective in altering the balance of Catherine's day. In the first five days of November she spent over twenty-three hours in the house undressed. In the first five days of December, January, and February she spent two, six and five hours respectively in a state of undress. Attempts to strip still occurred, however, so management of the behaviour still occupied a considerable amount of staff time. In order for the approach to be effective, a member of staff had to remain by Catherine's bedroom door, ready to offer her the opportunity to dress when she wanted to return to the household and to prevent her from doing so undressed. The approach was, in essence, a "time-out" procedure in which Catherine spent periods of time away from any possibility of gaining staff attention. She regained attention immediately upon dressing and continued to have the opportunity of attention as long as she remained dressed.

Although clearly effective, operating a "time-out" procedure such as this puts pressures on staff. For staff in this instance the procedure involved many occasions of boredom, waiting outside Catherine's bedroom door until she chose to rejoin the activity of the house. There was a temptation to avoid this boring wait by preventing Catherine from taking off her clothes in the first place. Staff had by now become proficient at getting Catherine to dress in the morning and after episodes of stripping. They were also better at intervening to prevent stripping, *but this strategy had to be avoided* as it represented a return to the habitual way of

responding to the first signs of stripping by providing Catherine with immediate staff attention. If staff did successfully intervene to dissuade Catherine from continuing to strip, not only was Catherine rewarded by gaining their attention but staff too were rewarded for avoiding the time-consuming management procedure. Prevention, therefore, was a tempting option. Even when they did try, staff could not always prevent Catherine from stripping. There were occasions when, if she wanted to continue to undress despite their attempts to prevent her, she would drop to the floor to counter staff correction. Being strong and fairly heavy she could usually remove some clothing whenever she wanted.

Prevention of Catherine's stripping had to be vetoed. The emphasis had to be on allowing her to take clothes off unconstrained and then to remove her from any situation in which she could gain attention. This approach had to be strictly established if Catherine was to learn that the consequences her behaviour brought had changed; that people were no longer going to respond in the way she predicted and desired. To emphasise this the function of stripping was defined and made known to everyone in contact with her: *Catherine was not stripping in order to be naked but in order for staff (or parents) to stop her, thus providing her with attention.* Everyone, therefore, must try not to attempt to stop her and must interact with her only when she began to get dressed again and for as long as she remained clothed.

By and large this emphasis was well-maintained. The frequency with which Catherine removed her clothing soon became relatively low. Even so, the approach was still time-consuming when Catherine chose to spend a long time in her bedroom before signalling her desire to rejoin the activities of the house. By this time Catherine was less heavy as a result of her diet, she was easier to work with, staff had become better at getting her to dress, and she herself was becoming more cooperative. In view of this the programme was modified to cut down the time it took. Catherine was taken to her room on stripping as before, but after a defined time staff would enter the room and dress her. The immediate consequence of this was that she spent less time in her room and more time involved in the life of the house. At this stage there were increasingly whole days spent without any attempt to strip.

While this was happening, the careful diet was having dramatic results. Catherine's weight reduced from fourteen stones to eight-and-a-half stones; from a dress size 20 to size 10. She has remained

about this weight ever since, moving up to size 12 and maintaining that size. Her skin and muscle tone were very loose after such a large loss in weight but these have tightened with time. Catherine's reduction in size greatly increased the potential for an overall improvement in appearance. The prospect was still marred by the continuing use of the blue suits, which were now not only stretched and worn through repeated attempts to strip but also voluminous. As Catherine had reached her target weight and was keeping the blue suits on for longer periods without stripping, it was considered that the time was right for a change to conventional clothing. This was achieved during the two-week summer closure of the day centre, seven months after Catherine came to live at 10 Summerton Road. Before moving on, however, another part of the story of her first six months at the house will be described.

Catherine's weight loss had other important consequences. The orientation of the house included developing a life in the community which was as full as it could be, given the limiting handicaps of the people living in it, and wherever possible to use the normal social means to achieve it. Going shopping was a significant part of the life of the household in which Catherine was involved. Helped by the reduction in weight, Catherine stopped using the wheelchair and was able to walk the distances involved quite easily. This gave the impression of a dramatic success early in the life of the house which may well have been important for staff morale. Complete strangers in town stopped staff to tell them how they had noticed Catherine about town for years (after all her appearance was distinctive) and how wonderful it was to see the rapid, recent improvement. Now she could walk! Of course she had already possessed this skill but it was certainly a boost for staff to be credited with this success.

The opportunity to walk, however, also allowed a new problem behaviour to emerge: Catherine would sit, or sometimes lie, down in the street. Again the behaviour was interpreted as being attention-seeking. It was decided that staff should respond by turning slightly away and ignoring her, while keeping a weather-eye open to make sure that she was properly supervised and did not escalate her attempts to gain staff attention to other behaviours which could be damaging. Luckily she never did. When she got up again, staff immediately gave her attention and the walk resumed.

There were some difficulties with this approach. Interpreting the scene as an accident, illness, or injury, passers-by asked whether they could help. Also it was not always possible for Catherine to be out alone with staff and therefore other people from the house had to stand and wait for her. Those who were verbal could not help paying her attention. Moreover, Catherine sometimes chose very unsuitable places to sit down; on one occasion in the middle of the road within sight of police in a nearby patrol car. Independent observation appeared to confirm the hypothesis of attention-seeking. Once while passing in a car, observers saw Catherine and a staff member in the street, with Catherine sitting down. Her eyes were riveted on the staff member and her face showed all the signs of a person waiting in confident expectation that her companion would turn and speak. Although the cause of a behaviour problem may seem clear, action to resolve it can be slow in gaining success. Catherine could sit for very long periods before getting up. If complete consistency in ignoring such behaviour is not achieved in this kind of situation, it is very easy to encourage the person to persevere with the inappropriate behaviour. Waiting for a while and then talking to Catherine might have taught her to carry on sitting down for longer. Staff may have been wanting to complete the trip for the sake of another resident, or because of embarrassment, and so may have inadvertently encouraged the behaviour by paying Catherine attention.

The sight of Catherine sitting down in town had repercussions for the general image of the new venture. A rumour began to develop in Merton which gave a detrimental account. Disquiet was voiced among a group of people connected with one of the local mental handicap voluntary societies. They were mainly parents whose children with mental handicaps, now adult, were still living with them, who might be future users of the service. The parents of people already living in the house, and others directly involved, were not included. A version of events was elaborated to the point that Catherine had been seen in a building contractor's car park (which is passed on the walk between town and the house), lying naked on the ground with a male member of staff on top of her. As far as it was possible to be sure, the event described was one when Catherine did indeed sit down in the car park and stay sitting there for some time. The staff member with her on this occasion was the person-in-charge of the house, who stood waiting

for her to get up and even had a conversation with the next-door-neighbour who happened to pass by. The reference to nakedness can only be accounted for by the fact that the rumour was passed throughout a network of people, some of whom knew that Catherine had a history of undressing and remaining naked.

It was perhaps true that in the early days of the house local parents thought that the new venture would not succeed, and that staff would fail to meet the philosophy to which they aspired. Moreover, there was some disagreement over the philosophy in some quarters. This principally concerned the level of demand being made of the people living in the house, the apparent lack of allowance for their handicaps, and the elements of risk which some of the opportunities for involvement in activities entailed; risks which some parents of people with mental handicaps avoided when looking after them at home.

It was important to respond to the rumour before a catalogue of disaster was assembled. The core of the group among whom the bad news was circulating appeared to be a regular social club of older parents who met as part of the activities of their voluntary society. As some of these parents had children who might be served by the house in the future, it was very important not only to correct the factual details of the rumour but to discuss the fears and concerns that might lie behind it. The person-in-charge contacted them and asked whether they would like to hold one of their forthcoming meetings at the house, when they could hear a presentation of the objectives and approaches being taken and have a chance to discuss their own views. That meeting was duly held. The presentation emphasised the positive things about the abilities of the people living in the house which staff were trying to develop and described the kinds of safeguards which had been established. Mrs. Henderson was present and gave her point of view and unconditional support. The meeting went well and, to our knowledge, there have been no more adverse rumours since. Some of the people who attended have begun to ask for short-term care for their children.

Having dealt with that issue well, there remained the immediate problem of how to manage Catherine's walking more effectively. At her first individual programme review meeting, which included all involved professional and service staff and her parents, it became clear that staff of the special care unit used a different method to deal with sitting down on the walks they took from the

unit to the local shops. As they usually went in a large group they had no alternative but to lift Catherine straight up again. Not for the only time, the value of having a multi-agency review system, in which all aspects of an individual's life and care programme across the board can be discussed, was brought home to us. As a result the staff of the house reviewed their strategy and decided, especially now that Catherine was lighter and could be lifted more easily, to follow the special care unit procedure. Sitting down was followed by a firm "No", a short command to get up, and a direct lift under the arms. The problem soon disappeared and Catherine subsequently progressed to such an extent that in the summer of the second year she was able to spend a week rambling in Dartmoor.

Developing Catherine's abilities and life style

By the time of Catherine's first individual programme planning meeting six months after moving in, significant progress had been made in reducing the frequency of stripping. Not only were there fewer interruptions to helping Catherine establish alternative behaviours, but staff were less preoccupied with managing the problem. The way was clearer for a concentration on positive development. Even so, the management of Catherine's stripping was still not completed; two more stages were to be passed through.

A change to use of conventional clothing was a high priority following Catherine's weight reduction. This was to occur simultaneously in the three settings which Catherine used: the house, the special care unit, and her parental home which she visited regularly. Catherine, her parents, and staff from the house shopped in preparation for the change, choosing mostly jeans and tee shirts, pullovers, and other similar tops. Everything was blue, the only colour Catherine would wear at the time. Encouraging her to wear other colours and a greater range of clothing, including skirts, dresses, and blouses, was to follow later. The collaboration which had already been established across all three settings was required again to achieve the change. As before, the house staff took the lead. The change to conventional clothing was made during the two-week summer closure of the special care unit. This enabled house staff to ensure that the response to *any* sign of stripping on Catherine's part was consistent under the new conditions of ordinary clothing. It was successful.

Having established the single, effective response already described if Catherine sat down when out walking, one objective set at her first programme review was for Catherine's parents to start taking her out for walks when she stayed with them at week-ends. Once this goal was achieved, Catherine's wheelchair was never used again. She became fully ambulant and was treated as such everywhere she went. The collaboration between house staff, day setting staff, and parents, which is so well-illustrated in relation to Catherine, is a fundamental idea within the system of individual programme review. Catherine's parents are particularly good. Whenever they have had Catherine home, they have been consistent in the way they have treated her, adopting the programme and teaching approaches used in the house. Several factors have contributed to their ability to maintain consistency on the key programme issues of the moment, including: regular contact and discussion; staff demonstrations of management techniques; and having each programme written down. Written programmes include a record of implementation and success as well as programme details. They can be shared by everyone involved and so act as an effective mechanism for maintaining consistency of approach in all settings.

Some major changes to Catherine's life and the way she responded to the people around her began to happen in the first six months or so of living in 10 Summerton Road. The key to her development from that point was in switching from a preoccupation with problem control to the development of pro-social behaviour. The first stages of this lay in teaching her to pay attention to people when they asked for it and then for people to pay attention to her when she was involved in an activity. It was still difficult and hard work for staff to keep up the high level of physical guidance and support needed to keep Catherine reasonably constructively engaged.

A major teaching objective set at the first review meeting was that Catherine should learn to make eye contact on request from staff and to give her attention to staff for a few seconds. Attending on request was formally taught using a graded teaching programme, set and reviewed weekly. Catherine willingly gave her attention to sweets, such as chocolate, and could follow the movement of them with her eyes. Small pieces of chocolate were used, therefore, to encourage her to raise her eyes and look at those of staff doing the teaching in response to the request,

"Catherine, look at me". Each time eye contact was made, a small piece of chocolate was given to Catherine as a reward. Gradually, Catherine had to look more and more towards staff members' eyes on her own, and the interval she maintained gaze was lengthened to a few seconds before she received any chocolate. After a few months of teaching, several times every day, Catherine was able to make eye contact on request unaided, and the use of chocolate as a reward was gradually eliminated. During this time, staff also concentrated on establishing as many natural opportunities as they could throughout the day when Catherine could attend to activities briefly but deliberately; for example, looking in a mirror, or doing simple hand/eye coordination tasks.

Health, appearance and relationship with her family

Parents of people with profound mental handicaps are used to changes being slow. The first year of Catherine's stay at the house was one during which her parents were constantly amazed (and delighted) at the changes made. However, to put her progress into perspective, few of the changes involved developmental growth—a very slow business for someone who is profoundly mentally handicapped. Most of the changes in Catherine's life involved differences in the behaviour of the people around her. This statement is not meant to diminish the work that was done, nor to belittle the significance of change for Catherine. But it does help to reconcile the seeming contradiction in the same person developing tediously slowly for over twenty years and then producing rapid change in a few months. Some people might view such change as in or of the person, and conclude that it might have been wrong to have viewed Catherine as being profoundly mentally handicapped. But she was and still is.

Change occurred because Catherine's diet was modified and, on a healthy, balanced régime, she had lost weight. Staff of the house and the special care unit, as well as Catherine's parents, had agreed a way of responding to her so that she stripped less often and ceased to sit down when out walking. They had bought her new clothes and attended to aspects of her appearance. They worked hard at bridging the gap between Catherine's personal ability and the competencies required to become involved in a full household life. They were directive and supportive rather than permissive: Catherine was not allowed to do exactly as she chose.

Catherine had thin, straight hair that did not grow very well at

the back. She began to go to the hairdresser regularly and, with skilled styling and attention, her hair gained body. She drooled badly; the dribble was unsightly on her chin and made a wet area on her clothing underneath. Effort was put into teaching her to allow time to swallow properly at mealtimes, but a review of her medication may also have had a significant impact. Part of the comprehensive review of Catherine's needs addressed the level of tranquillisers she was prescribed and resulted in a reduction of the drug Haloperidol. Following this drooling ceased to be noticeable and this had an immediate beneficial impact on her appearance. Its greater significance, however, may well be for Catherine's long-term health. Such drugs are powerful and not best taken routinely throughout life. With regard to Catherine's excessive facial hair use of a proprietary depilatory cream was effective. Staff then began to investigate how cosmetics would enhance her looks.

Again, it is important to emphasise that, in looking at the action taken in this area, little was to do with changing the ability or skill level of Catherine herself, a woman with a profound mental handicap. It mainly concerned staff activity. Appearance does seem to have an effect upon how a person is regarded by others. If appearance is poor it tends to emphasise the handicap. If appearance is good it promotes the semblance of greater capability. We have shown photographs of the people living at 10 Summerton Road in presentations to staff from other residential settings and have been unable to convince some of them that all of these people are either profoundly or very severely mentally handicapped. The popular association of appearance and extent of handicap is very strong.

Later in Catherine's story behavioural change and change in appearance began to go hand-in-hand. Given a greater head of hair and degree of styling, learning to brush her hair took on greater importance. Her walking improved and she lost some of the ungainliness of her gait. The habit of always wearing flat sandals was changed and her footwear became more fashionable. She was being taught to sit still for longer periods — a matter of seconds at first and then minutes. The impact of her changed appearance and her new-found ability to remain seated in a social group is vividly illustrated in a story told by Catherine's parents. It was a long-standing family custom for the Hendersons to visit close relatives on Christmas morning. After the parents'

generation had been chatting for a while, one of the hosts asked, "Where's Catherine?". She had not been recognised as the same person who had visited the previous year. The degree of change had a similar effect on members of the public. A passer-by asked one staff member accompanying Catherine on a trip to town, "Where's the big girl who used to sit down in the street?".

Catherine's relationship with her parents has continued to be a significant part of her life following admission to long-term care. Like Shirley, contact with her parents has been frequent and regular. If anything Catherine has spent even more time in their company; she has gone to stay with them every other week-end, virtually without exception. At first, apart from occasions when her parents came to the house for special social evenings like a New Year party, this was the main form of family contact. Initially both parents, but Catherine's mother in particular, found that short visits to 10 Summerton Road were not helpful because they seemed to upset Catherine. Their arrival seemed to start Catherine stripping with a degree of persistence which would endure even after their departure. However, when staff began to find that the approach within the house was effective in lessening attempts to strip, they began to work with Catherine's parents to help them to carry out the same approach at weekends. Mr. and Mrs. Henderson's contribution and application were superb. They began to get the same results. Although when staff and parents were together Catherine's stripping could still be a problem, her parents began to report complete week-ends during which there had been no instances of stripping at home; something which had taken much effort over many months to establish. Gradually, Mr. and Mrs. Henderson were able to visit 10 Summerton Road without occasioning Catherine to strip. Contact between home and family has subsequently developed freely and without constraint.

Catherine's parents were encouraged to visit her at the house more often, even when there was still difficulty. However, staff and parents realised that, since moving to the house, Catherine was not seeing as frequently the relatives and friends she used to visit with her parents when living at home. Through the individual programme plan system, it was decided to try to keep up the level of these contacts by staff taking Catherine to visit people in her own right. Her parents readily agreed to provide introductions. It was also made clear that friends and relatives could visit

Catherine. If they were in any way shy, they were welcome to come first in the company of Catherine's parents. As a result, Catherine continues to see various friends and relatives independently as well as in the company of her parents.

Catherine's parents and the staff of the house have developed a firm basis of mutual trust and collaboration. They have acted together to formulate and implement a systematic response to Catherine's stripping, to encourage her to walk, to deal with inappropriate episodes of sitting down, to promote self-feeding and improved table manners, to encourage her to remain seated in company, and to arrange their own and other social contacts with Catherine's welfare foremost in mind. Their mutual respect has made it easier to discuss issues of considerable sensitivity, such as whether Catherine should continue to receive injections of long-acting contraceptive medication and whether she should be given contraceptives at all as a routine precaution, and whether in view of her poor teeth she should wear dentures. Both issues were discussed extensively. Contraceptive medication was discontinued. Her parents were not keen at first that she should have false teeth because they thought she might choke on them, so initial dental care centred on restorative work. The feasibility of provision of dentures was subsequently investigated with Catherine's dentist. During the writing of this book, dentures have been fitted and Catherine is learning to use them.

Development and behaviour problems revisited

There is a coherent body of opinion in behavioural psychology that views behaviour problems as an elementary form of non-verbal communication. Catherine had few skills, was deficient in giving attention, found learning extremely difficult, and had only a few words by which to express herself to others. The natural history of the behaviour problems she exhibited seems to fit with a communication hypothesis. The behaviours did not simply disappear; they at first changed in frequency, and then took a different form. They cannot be viewed as permanently replaced. Staff and parents are aware that stripping may return and that they may need to reapply their systematic response to it.

As Catherine's appropriate skills develop and she becomes more able to lead her own life and to communicate with others, she may leave behind such inappropriate behaviour permanently. The fact that such behaviour is likely to return periodically,

however, should not be viewed as failure but as a healthy sign. It may show that Catherine's life is not standing still, that new and more difficult things are being demanded and expected of her, and that she is beginning to lead her life without constant adult attention. The important issue is that staff and parents must not be deflected by the absence of a permanent "cure" from returning when necessary to the use of their previously effective approach.

In the first section on Catherine's development, we covered the initial six to nine months in the house: the first stage of the control of stripping, the return to full ambulation, the control of sitting down in the street, the return to conventional clothing, and the teaching of the behaviour of making eye contact and paying attention. These changes provided the basis for continuing development.

The programme to reduce stripping, however, was not complete. Catherine was much improved in this respect but, although remaining undressed for only short periods of time, she still occasionally took off her clothes. Once the blue suits had been discontinued, removal of clothing was restricted to her tee-shirt or other top. A close scrutiny of her behaviour showed that there were two topographical forms to which people had been responding as if they were both part of the same event, namely stripping. (The topography of a behaviour is the description of the precise action, that is, form that the behaviour takes.) One was a right-handed tug upwards from the left side of the neckline of her tee-shirt or other top. The neckline of the garment would be pulled up to about eye-level. Then Catherine would pause and look at staff, and would either stop or continue tugging depending on their response. If staff told her not to do it (that is, gave attention) she would stop. If staff did not respond she would continue. This "tugging" was a high frequency behaviour which acted as a constant irritant and source of interruption. It also damaged Catherine's clothing so that most of her tops became stretched and distorted at the neckline. The other topographical form was a direct removal of her top clothing. To accomplish this, Catherine's right-hand grasped the bottom edge of her top, she lifted her arm straight above her head in one movement, and removed her top in one go.

The recognition of the two different forms of behaviour necessitated a development in the hypothesis concerning the function of Catherine's stripping. Initially attention-seeking had

been seen as the reason for the behaviour. A second cause, demand-avoidance, was now added; that is, the ability to stop a task or to avoid a demand. It is likely that Catherine's stripping had always been motivated by both factors. This would help to explain the variability in the length of time Catherine would choose to stay in her room before seeking to re-establish the company of others. The programme was now revised to take account of the likelihood that the two forms of behaviour had different purposes: that the tugging was designed to attract attention, and that full removal of her top was designed to bring current activity to an end and enable Catherine to escape from a situation which made demands on her. The approach to be used by staff to deal with the behaviour was therefore modified as follows:

staff must give Catherine attention at a high rate when she was busy and particularly when she used appropriate forms of communication (words or gesture);

tugging at the neckline of clothing must be greeted by a curt instruction to pull her top down, staff directing both her hands to the bottom of the garment to pull it straight;

staff must be sensitive to activity length and activity difficulty, in an attempt to avoid Catherine wanting to escape from situations;

staff must continue to exclude Catherine from the communal life of the house for a brief period following removal of clothing, dressing her again at the end of the period and then re-engaging her in activity.

As the new approach was adopted the place to which Catherine was excluded was changed from her bedroom to the bathroom. Now that Catherine was becoming involved in hair styling, grooming, and the use of make-up, she found her bedroom a pleasant place to be. It was therefore thought to be an ineffective place to which to continue to exclude her, particularly as a time-out strategy was no longer regarded as the most obvious management approach. If the hypothesis that Catherine was signalling a wish to stop an activity was correct, going into "time-out" was one way for her to achieve the desired outcome. In these circumstances, stripping might be expected to persist. Added to this, staff did not want Catherine to regard her bedroom as a place of punishment.

This change in strategy soon made an impact in a fairly dramatic way. Catherine spent a turbulent week-end in the house when she damaged property and pulled staff members' hair. She tipped over and broke her own record player and she pulled curtains down from the rail. All these behaviours were familiar to her parents, Catherine having displayed them in the past. It seemed that in the frustration of finding her dominant problem behaviour being blocked from achieving its accustomed ends, Catherine was bringing in others from her past experience. The person-in-charge of the house was called in for advice. Staff responded calmly, knowing that a wrong response by them to the new behaviours could easily establish them as an ongoing problem. By Monday evening, the tantrum had subsided and the new behaviours fell back into abeyance. Catherine no longer tugged at the neckline of her clothes.

Periodic bursts of stripping still occur occasionally at the house. As we have said, this may be a healthy sign — that staff require more of Catherine as she develops; but they may sometimes make the mistake of demanding too much from her, either in terms of length of attention or complexity of activity. In response Catherine may show signs of stripping and, because of the length of time since they last used the set procedure, staff may naturally respond by trying to prevent her from doing so. Finding that the old consequences of her behaviour are back again Catherine quickly increases its frequency. The set programme is then reinstated. Having experienced this natural cycle of events staff have learned from it. They now know the perils of doing anything other than following the laid down procedure. Their learning has been reinforced by the fact that when they have followed the procedure they have avoided an increase in Catherine's attempts to strip.

Stripping has also continued in the settings in which Catherine spends the day, seemingly as a result of inconsistency in management. The problem is greatest in the special care unit where some days are dominated by Catherine stripping repeatedly, a fact that illustrates the specificity of the relationship between individuals' behaviour and their immediate environment. Just because Catherine has learned not to do a behaviour (that is, the behaviour is ineffective) in her own house and that of her parents does not guarantee she will not do it in a third setting if staff there do not manage it appropriately. Given

that management within the special care unit has not been entirely successful there have been short-term carry-over effects when Catherine has returned home. However, these have lessened with time.

Having succeeded in greatly reducing Catherine's prevailing form of stripping (the physical removal of clothing), staff and parents were next presented with a verbal variant: the request "change". Catherine asked repeatedly to change her clothing. This she did at any time throughout the day but, possibly due to the carry-over effect already mentioned, she asked most frequently following return from the special care unit. Initially staff and parents indulged the request, finding it distinctly preferable to actual stripping. After some months however, this behaviour too became tedious and wasted a considerable amount of everyone's time. A concerted attempt by staff and parents to refuse the request met with success.

Work on developing more positive aspects of Catherine's life continued. The initial teaching of attention, together with the constant daily practice of participating in the household routine, was beginning to result in a greater willingness on Catherine's part to stay in one place and become involved. The length of time she would sit down in a social situation gradually increased. She became able to go to a pub or café and behave appropriately and to sit patiently at the hairdresser's. There has been a remarkable achievement in respect of dental work. Whereas before all dental work had to be done under general anaesthetic, more recently a local anaesthetic has been sufficient, with Catherine voluntarily sitting long enough to allow the treatment to be undertaken.

While basic attentional control was being taught, simple self-care skills were also being targeted. Catherine was taught to eat using a fork and spoon together and, following this, to chew her food more slowly and to swallow well. She had always eaten with her chin well forward, over and almost in her food, so she has been taught to sit up straight and to raise the food to her mouth. Towards the end of her second year in the house, she had progressed to eating with a knife and fork. At about this time, teaching of dressing was begun (she could undress well already!). She was also taught to wash herself and to sit longer for an activity.

About the house and in town Catherine is able to do most things with the support of staff. She participates in all types of food preparation, clearing away, domestic, and laundry tasks in the

house; she joins in the gardening; and she goes shopping and visits pubs and cafés, the hairdresser's, and the theatre. She has begun swimming, not in a special class or association for the disabled, but as an ordinary member of the public. The skills she required in all these activities were identified and taught, such as: the ability to sit in a pub after finishing her own drink while others finished theirs; how to clear the table after a meal; and how to take rinsed dishes from the sink and place them on the drainer.

Throughout this time, but particularly after the initial management of difficult behaviour was accomplished, it has been important to encourage Catherine in her use of language, both in the breadth of her vocabulary and in the sophistication of her expressive speech. She has changed from having a few single slurred words to having a considerably expanded vocabulary, a clearer and more adult articulation, and the ability to use words in pairs and phrases. Her most sophisticated utterances now are simple phrase and sentence constructions of up to about four words. A recent teaching goal is for her to learn to sit, look at a picture, and have a conversation about it with someone for three minutes.

Catherine's dressing has improved and she can now put on her own pants, tops, jeans, and shoes. She still needs help with her bra and with tights. Even so, on the occasions, rare now, when she strips she has the dressing skills necessary to regulate for herself how long she need stay away from the mainstream life of the house.

Current life

In this account we have tried to convey an impression of considerable change, which has had a dramatic impact on one person's life style and which has the potential for even greater possibilities. Catherine's way of life has shifted from that of an overgrown, difficult child who lived at home and went to bed early, to that of a young adult who keeps adult hours and shares a daily routine with others that is similar to that followed by the general community. But not by any stretch of the imagination has Catherine been made normal; she will always be regarded as having a profound or very severe mental handicap. Currently a programme is under way to try to establish night-time continence and her coordination is so poor that she is working on a target designed to enable her to drink from a cup without spilling. She

follows an exercise programme to tone up her muscle structure, partly to tighten up her skin which was stretched by being so much overweight but also because, like many other people with profound handicaps, her limbs have been relatively underused in the past. But perhaps in the fitness boom of the eighties having such a programme is not unusual!

Catherine lives independently of her parents, in a staff supported house in the town in which she has grown up. She is likely to continue to live there for many years to come, if not the rest of her life, should it suit her and should she require it. Monday to Friday she attends the special care unit of the local adult training centre, as she did before moving to the house. The curriculum there resembles one for nursery or infant children, and during the past three years, Catherine's programme has changed little *in character* although it may have changed in detail. That does not mean that there have been no successes in teaching her specific skills or that changes in routine have not occurred. For example, Catherine has made progress in naming pictures and she no longer eats her lunch in the special care unit itself, instead taking lunch in the main dining hall. But the contrast between her working life and her home life illustrates the interaction that can occur given certain characteristics in the setting and the personal characteristics of an individual.

Catherine is the same person in both settings. The changes in the character of her life at home have come about in a setting designed to offer the same opportunities that people who are not handicapped enjoy in similar settings. It is the job of the staff to exploit these opportunities ingeniously and deliberately, to the maximum benefit of the individual who is handicapped. A hard look at the special care unit, on the other hand, reveals a setting which possesses few of the opportunities usually available in work places for staff to exploit. The staff are as handicapped by the environment of the unit and the orientation it generates as the service users.

On week-days, Catherine returns to the house around 4.00 pm. She may attend first to personal concerns but then there will be chores to be done. These vary from helping to prepare the evening meal, cleaning her bedroom, doing the washing, or going shopping. Usually the evening meal is taken between 6.00 and 6.30 pm. Sometimes, the people who go shopping at the end of the afternoon eat out and do not return until later. After the meal, the

washing up must be done and everything must be put away. People usually have a cup of coffee together, either directly after the meal or a little later. Some evenings Catherine goes out: to the pub, or to the house of a friend or relative, or to some recreational event. Sometimes she has visitors. Sometimes she just stays at home, perhaps doing some housework, or enjoying the chance of a longer bath than usual, or involved in a one-off activity with the others, or following an interest of her own. For example, she has begun to use a camera and is assembling a photograph album. She usually goes to bed some time between 9.30 and 11.30 pm, possibly later on special occasions.

Catherine goes to stay with her parents on alternate week-ends. These occasions are pleasant for all concerned. Her parents involve her in more activities these days. She helps her father in the garden. Sometimes they go out and watch a game of cricket. She shows pleasure anticipating a week-end with her parents. Afterwards she is also clearly happy to return to her own home. Her parents visit her on the week-ends she is not staying with them and they often call in mid-week too. Catherine sometimes "drops in" on her mother for coffee.

Each year the people living at 10 Summerton Road go on holiday. They go in pairs, together with two members of staff, to a place of their choosing. In the first summer, Catherine was still seen as someone who presented major management problems. The holiday chosen for her was a number of successive day excursions, returning to the house every evening. In the second summer, Catherine went for a walking holiday in Dartmoor. The next year she went to stay in a rented cottage on the coast. The accompanying staff were surprised by the independence she displayed on this last holiday; advances over and above those that had developed at home. She was content to sit in the cottage for long periods and she was particularly communicative, speaking in short sentences. She started helpful activities on her own. For example, she set the table, asking for help to find the things to be laid. She tidied up unprompted, picking up any clothes on her bedroom floor and trying to put them away. When she had finished with her coffee cup, she took it to the kitchen and put it in the sink. At dusk she drew the curtains in both rooms of the cottage and switched on the light without being asked. In fact she was generally helpful with household tasks and needed less physical guidance than usual. Staff also noted how well she had

accomplished some self-care skills. For example, she ate more competently, using a knife and fork. She needed few reminders on how to stab food with the fork and she remembered to put her knife and fork down between mouthfuls giving herself time to chew well and eat slowly. She did not wear an apron (as she usually does in the house) and made little mess.

Mr. and Mrs. Henderson's view

Catherine's parents have this to say about the impact that the changes of the last three years have had on their lives:

Mr. H.: *"The difference it has made in our lives since Catherine has been away is that it has taken all the tension out of it. We used to be on duty twenty-four hours a day. Now we can relax, and it's the first time we've really relaxed for 22 years. We are living a totally different life and enjoying life; relaxing, which at our age we need to."*

Mrs. H.: *"We were just about at the end of our tether, I believe. I felt that life was like a spring wound up which was going ping all the time and I was really worried. It was at least an eighteen hour day. I don't watch the clock now as I did then. I knew other people watched the clock and had time settings for everything. I did. I didn't have very much time for myself really — you could say from 10.00 in the morning til 3.00 in the afternoon — and there had to be a lot of work done in that amount of time. I had to do all my work, shopping, go to the hairdresser's, and get all the housework done at home. Catherine would be up anything from 5.00 am onwards and it was a case of working towards going to the Special Care Unit at 10.00. Very often, we would be ready earlier. We would have long bathing sessions but still be ready to go to the Centre far too early. I would take her out and drive her around in the car until it was time to get there. The other people going to Special Care, the ones that did get there early, were the ones who came on the organised transport. I took Catherine every day and fetched her. I think I was supposed to collect her at 3.00 but I did not go until 3.30 to pick her up — well, between 3.00 and 3.30 anyway."*

Mr. H.: *"We used to spend hours and hours, travelling miles and miles, driving around just to keep Catherine happy. It was far better than being in the house where she appeared to be unhappy — well, not so much unhappy but naughty — driving round and round, it*

was a way to pass the time. Really we passed our life away just to keep the peace with Catherine."

Mrs. H.: *"Yes, that's quite true. We tried several things, but we weren't very happy about her going away. The happiest time was when she went to the Junior Training Centre in (town) during the week and came home at weekends. That seemed to work very well but, of course, when she became sixteen and an adult she had to change over to the Training Centre here."*

Mr. H.: *"We always said that that had a lot of effect on Catherine, didn't it?"*

Mrs. H.: *"Yes, change."*

Mr. H.: *"It was strange. She was happy to go away for the week and come home weekends and was happy to go back again. When she had to leave . . . she became extremely naughty."*

Mrs. H.: *"Very difficult."*

Mr. H.: *"Very difficult, yes. Because she missed the school. She didn't like the change. That is Catherine's biggest problem, it's change. I think they find this with new members of staff: new faces. A new person comes and she tries to play them up and get the better of them — until she's beaten them — and in the end it's anything for a quiet life".*

Mrs. H.: *"It's quite true."*

Mr. H.: *"At the Special Care Unit, they followed the same approach as us — is there anything to keep Catherine quiet? When they started up at 10 Summerton Road, they started with a completely new method and stuck with it. That is what has proved to be the right thing, in Catherine's case."*

Mrs. H.: *"We've tried to follow that method as well but I don't think they have always been able to do that at Special Care."*

Mr. H.: *"We would never have thought of letting Catherine do things herself because we would do everything for her. We kept her away from touching anything. The method at 10 Summerton Road, to make her do things and make her be as independent as possible, has worked. If you could see Catherine when she went into 10 Summerton Road and now; they have worked absolute miracles. She is a thousand per cent better because she has been made to feel*

like someone, I think, feel like a human being in her mind. She is someone now, before she was nothing. I'm sure, in her own mind she feels that way. She is living in the community now. She goes out shopping, where we pushed her around in a wheelchair. She wouldn't walk more than half-a-dozen steps without sitting down so we had to get the wheelchair just to be mobile. We can now arrange things we could never have done before. We can now go places we could never have gone before. Prior to Catherine moving into Summerton Road, if ever we were invited out or asked to join in something we said, 'We will have to wait to see if we can get a babysitter'. We could only ever get one person to babysit because she was the only person Catherine would accept. They seemed to hit it off and get on with one another, and Catherine was very fond of her. So we always had to get in touch with her first: 'Can you come on a certain night? Yes? Then we can make arrangements'. We daren't make any arrangements beforehand with the fear that the babysitter wasn't available. So in that way our lives were completely tied down. Now we are free to say, 'Yes, we will go down there' or 'We will do this', and plan ahead. We couldn't plan more than a day ahead before, could we?"

Mrs. H.: *"No. I worked nights and people used to invite me to do things during the day. I could only agree to things between 10.00 and 3.00 but I always used to say, 'Yes, God willing'. People had to understand that I might not be able to, for if Catherine was ill then that was it, I couldn't go. Even though she was that age, I was still curtailed as if I had a toddler.*

I haven't yet said about how easy it was going to be having Catherine in Summerton Road. She would be on my doorstep. But I didn't realise how much I would miss her, and that I would still be watching the clock and I would be thinking, 'Yes, she will be coming out of Special Care just now' and wondering what sort of day she had had. In the morning, I would think, 'She is just going now', and I was still watching the clock even though she wasn't here."

Mr. H.: *"In the evening, we would sit and talk, wondering what she would be doing, wondering whether she was behaving herself. I think it was out of relief as much as missing her. We could sit back, relieved in our own minds, and be able to talk; hoping she would make it, because we always had our doubts that her behaviour problem would be too great and we would see her back on the*

doorstep again."

Mrs. H.: *"Yes, I did worry about it."*

Mr. H.: *"We worried whether she would make it."*

Mrs. H.: *"We haven't had a very easy time with other people looking after Catherine. It's always a strain and we've always had the feeling that it's been very difficult for them. When we've got back when we have been away it was clear it's always been very difficult for them."* (Do you mean for services?) *"Yes. They never told you when you were away, but when you got back. We always realised that Catherine had been quite difficult."*

Mr. H.: *"She went into two hostels while we went on holiday and each time she caused havoc. When we 'phoned up while we were away they had said, 'Don't worry, she's OK'. When we got back they hadn't coped with her and we would suffer terribly for two or three weeks after that, while Catherine would appear to take it out on us for leaving her there. And then, in the later stages, we went for three or four years without a holiday. Then we were talked into letting her go into . . . Hospital. She went in there on two occasions and she came out in such a state on both of these occasions that we vowed we would never let her go again. We always said that we didn't blame the staff because there were only two staff to 30 residents and, no matter how hard they worked, they couldn't cope."*

Mrs. H.: *"She went into . . . Hospital for a weekend once a month because when we knew Summerton Road was going to open we thought we would try to get her used to going away. Do you remember that?"*

Mr. H.: *"Yes. We had a programme of stays. The consultant psychiatrist asked for that to give us a break because we were really getting to the end of our tether. Terrible, the trouble is remembering what we felt. It's very difficult to remember. We feel very rested now and we were very, very tired then. It's a funny thing, people ask how we coped, but it became an everyday pattern of life for us. We never thought about not coping. It was part of our lives and we really forgot what life was all about, normal life. Other people enjoying life could not understand it. We were so tied down and said, 'We can't do this', 'We can't do that'. They'd say, 'Why can't you do it?'. They didn't realise. We just took it for everyday life. We didn't*

complain about it."

Mrs. H.: *"I always said that whatever you have got to do, you can do. Whatever life presents you, if you are determined, you can do it."*

Mr. H.: *"It was our burden and we carried it. It became natural life for us in the end. We can honestly say that when Catherine went into Summerton Road we were lost. We were walking around, no noise, no havoc, no tension — we were lost."*

Mrs. H.: *"The tension was quite severe, like being on a spring all the time. For instance, when cooking I was always scared of her being burned. Something happens and you think, 'What shall I do — turn it off, take it with me?'. Catherine would never come with me if there was something on the cooker. If the telephone rang when I was cooking, it could cause havoc."*

Mr. H.: *"And in the latter stages when she was stripping so much, if anyone knocked the door — well, there was all hell let loose while we tried to get her into her room. One of us would sit in the room with her while the other opened the door."*

Mrs. H.: *"I was on my own and the door used to go."*

Mr. H.: *"Yes, or in the evening, when Mrs. H. worked, there was me keeping them standing on the doorstep and trying to push Catherine back saying, 'Would you hold on a moment?', explaining in the end that I had a handicapped daughter and I didn't think she was fully dressed at the time and could they just hold on. And if they had to come in, to try and whip them into the lounge and try to get Catherine to see a little bit of cooperation; and if not put her in her room. You had to put her in her room and leave her there while you spoke to the person. It was terribly difficult dealing with strangers."*

Mrs. H.: *"I found that, of the tradespeople coming in, the insurance man was the most difficult. You would have to go into details . . ."*

Mr. H.: *"Catherine would burst out with nothing on."*

Mrs. H.: *"I'd have a cheque written out. I got very skilled at getting things done very much in advance. I'd get the cheque all written out, you know, and put ready."*

Mr. H.: *"If someone came to the door we had to put Catherine into another room, close a couple of doors to give us a chance to sort the*

person out before Catherine got out and got to the front door. The tension was that great."

Mrs. H.: *"So it's very difficult now to assess how we felt."*

Mr. H.: *"It seems an age ago. It's three years ago and it seems an age — as though we never really had it. It's just something that you have to rake your mind about to know what really did happen. It's very difficult to picture now. Looking back on it, I don't think we could have carried on much longer. Summerton Road opened up just at the right time to save us, I think. One of us would have gone I am sure of it, because at times we felt terribly ill. The lack of sleep was one of the worst things. I had meetings at work, having been up since 4.00 in the morning, and I found myself dozing off and it became a worry. For your job you know. You felt you were slipping behind because you couldn't get to grips with it — you were so worn out. Although we used to share as much as we could . . ."*

Mrs. H.: *"I used to do everything during the week really and you used to cover weekends. And you used to say I could catch up on my sleep then but I really couldn't. I used to fall asleep sometimes. If I dared to sit down in the afternoon, I'd be away. Mrs. R.* (senior instructor at the Special Care Unit), *to give her credit, used to say if I didn't get there on time they would say I'd fallen asleep and they would leave me and then would ring about 4.00. It was like having a heart attack when the phone rang. I would tear up there and fetch her. I would fly in and make all my apologies and they would say, 'We knew you were asleep, you must be asleep'. Perhaps about once a month I would do that. I used to find that I could hardly crawl out to go to work at 6.00 o'clock. About an hour later people used to say 'You look better now'. It was when I would begin to relax. I went to work to relax."*

Mr. H.: *"The doctor actually said that it was a good thing for her. It was fortunate that she could go to work in the evening and that I could come home and take over."*

Mrs. H.: *"That was the only reason I could do it. I would not have had a job if I hadn't found out that they took night staff. So I applied to go back. I couldn't do a day job because I knew I couldn't keep it up if Catherine was ill or in school holidays — you couldn't keep a job going. That was the thing that kept me sane, going to work kept me sane. If I couldn't have I would have been in a mental illness*

hospital myself, if I couldn't have gone out and had some privacy."

Mr. H.: *"And then it got to a stage that we could never take Catherine anywhere, to anybody else's house, without her being terribly naughty unless she got her own way. So we just stopped taking her out. Now we take her down to Paul and Anne's* (brother and sister-in-law) *and the grandchildren, and she is good as gold there. And recently we took her down to my sister-in-law in Somerset and we had lunch down there and came back in the afternoon and they were amazed, weren't they? They never thought they would see Catherine acting the way she did. Paul said he never ever thought he would see Catherine using a knife and fork. She will sit at the table now with a knife and fork, whereas before it used to be head down bolting away at her food. It's absolutely remarkable the progress she has made. Everybody, our friends all state it, what a remarkable change. She's a different child — oh yes, I mustn't say child — sorry, I always say that.*

To us, Catherine was always a baby, wasn't she? A baby. We used the term babysitter when we shouldn't have done. We still did that when she was 20, she was always a baby. Now, Catherine appears to us more as an adult. She's far more intelligent, she must have had intelligence there before but she shows more intelligence. She is so well behaved now. It's difficult to say, we've loved Catherine always; but there were times we got to the end of our tether with her — oh God, feeling anything but love at times — but we never ever smacked her, we never scolded her. Well, we might have scolded her but we never smacked her, did we?"

Mrs. H.: *"No."*

Mr. H.: *"We refrained from that, but I think the affection, that's the word I think, is growing now with her because she is so good. She comes home at weekends now and she is so good that you are proud of her. Yes. Whereas before you could not feel proud of her. You can feel proud because she has made so much progress and she's so much warmer to us, isn't she? When she comes home now, weekends, we'll sit in on a Saturday night, the three of us, on the settee, and watch the television. It's been up to two hours, Catherine sitting with her head laying on you and actually watching the television. Three years ago she wouldn't sit down for two seconds. She just wouldn't sit down in fact. And now, she'll sit down for long spells; and she'll sit at the table after she's had her meal and wait for*

the others to finish."

Mrs. H.: *"We are enjoying our time with Catherine more."*

Mr. H.: *"We look forward to her weekends, coming home."*

Mrs. H.: *"We don't really relax much when she's at home do we, even now?"*

Mr. H.: *"When she's home we devote the whole weekend to Catherine. We made up our minds that every other weekend we would make no arrangements unless it was to take Catherine visiting, or something like that. The whole weekend is devoted and centred around Catherine and, for all the rest of the time, we are absolutely free agents. We've never known that in our lives before."*

(Are there any other sorts of things that you do now? Things you spend a lot of time on where you couldn't or didn't before?)

Mr. H.: *"Sit down."*

Mrs. H.: *"Enjoy our own home, I think it is one of the greatest pleasures, do you not think so? Strangely enough, although we say we can go out, we don't now, not so much as we did."*

Mr. H.: *"We used to go far more when Catherine was at home than ever we do now. Since Catherine has been at Summerton Road, I don't think we go out a third as much as we used to — it was getting out, getting someone in to look after Catherine and just getting out we wanted; but now we don't want to. We've got the house and the garden and we are happy to spend our time at home in peace and quiet and I think that's one of the main things — peace and quiet."*

Mrs. H.: *"We do live quite busy lives, although I complain that I'm not doing as much as I did. I haven't got the strength. But it's still quite a busy life really. You know, the girls at work tell me I do too much."*

Mr. H.: *"I go to quite a lot of meetings you know, but hopefully I shall start curbing those."*

Mrs. H.: *"I don't know what I'm going to do when I retire next year if he's out as much as he is. There comes a limit to the amount of charity work you can do."*

Mr. H.: *"I have to go to a lot of meetings for the firm."*

Mrs. H.: *"I know you do."*

Mr. H.: *"Well, I would say that Summerton Road has put ten years on our lives and I mean that sincerely. I thank Summerton Road for saving our lives and I say that with all sincerity. When we heard that Summerton Road was opening and that it was for people with profound handicaps, we almost did a highland fling — when we thought there was a possible chance for Catherine. As we said earlier, we did not think she would survive — with her behaviour. We don't mean any disrespect but, at the time, we were scared that they wouldn't be able to handle her."*

Mrs. H.: *"Well, we'd had so many bad experiences."*

Mr. H.: *"Nobody ever handled Catherine."*

Mrs. H.: *"And we weren't making a very good job of it."*

Mr. H.: *"No, we made a hash of it in the end. It's our fault in the end. We had to give up trying to keep Catherine dressed, otherwise we wouldn't have done a thing. We couldn't have decorated, we couldn't have done anything in the house unless we had let Catherine strip. When she'd done it Catherine would be happy and would sit down or walk up and down and we could get on with any work. It came to the point, when we were trying and trying to keep her dressed and trying to keep good behaviour, when we were doing absolutely nothing."*

Mrs. H.: *"And it's not just one day. It was day in, day out; week in, week out."*

Mr. H.: *"Everything was getting neglected, trying to look after Catherine."*

Mrs. H.: *"You know the outlook has changed such a lot. When Catherine was a baby we were told at Great Ormond Street never to expect very much, not to expect anything. You were not given any guidelines. It's bad enough I think for ordinary parents. Parents have a great responsibility with an ordinary child. I have always thought that parents don't realise what they are letting themselves in for. It's a great responsibility, and everyone has to have trials and errors; but, with a handicapped child, it's even worse and you were not really given . . . well, perhaps you are now . . . given advice. And you didn't really think about it — you always thought that what she was doing was because of her condition. You didn't relate it to the fact that she was just like an ordinary human being who didn't*

have the ability to learn quite as well. So, you always felt it was to do with her disability; it was her brain telling her to do something, when really she should have been treated just normally. This sitting down business — if you had a toddler doing that, you would leave him sitting in the street and walk away. You'd say, 'I'm off, and if you are not coming . . .'. When you get somebody aged twenty doing that, then it becomes very difficult."

Mr. H.: *"She was so terribly heavy that you couldn't pick her up. It was impossible to move her because she had some built in way of preventing you from lifting her. She would lie there in such a way that you just couldn't move her; she was a dead weight."*

Mrs. H.: *"Well, I certainly could not go back to doing that again, so I hope that houses like Summerton Road will survive. Well, I wouldn't have to because she's changed, hasn't she?"*

Mr. H.: *"Well, I'm sure that they will survive and the only thing that I hope is that Catherine stays at Summerton Road for the rest of her life. One thing Catherine does not like is change — I think we are all agreed on that. She changes her attitude when there is any change, so I hope to goodness that she stays at Summerton Road and I'm sure she will always be very happy there.*

One of our biggest worries was that, before Summerton Road opened, we knew that if anything happened to us Catherine was destined for a mental hospital. With her behaviour problems, she would have gone into rather unpleasant surroundings. That was one of our biggest fears; to try and face up to the fact that that was where Catherine would end up. Because it was obvious. We always said to Paul, 'You may feel as though you want to have her but you must never burden yourself with her; but always make sure she is well looked after'. You see, that is another thing that Summerton Road has taken care of — it's taken the burden off our minds. What's going to happen to her when we are gone? Now we know that she is going to be safe and happy.

We said earlier that we used to go every Christmas to friends for a drink on Christmas morning. If Catherine was not happy, we used to be there for about three minutes and one of us would have to come back. This was before she went to Summerton Road. It was last year our friends didn't even know Catherine was there. They said that they didn't realise that it was Catherine. It was absolutely true. She sat down for an hour or an hour-and-a-half."

Mrs. H.: *"I don't know, I didn't stay there drinking too long because I see three turkeys if I do . . ."*

Mr. H.: *"They said, 'That's not Catherine because she's slim and good and she's sat there on the settee with Paul and Anne'. It just wasn't her, for usually she took over; she was the centre of attention wherever she went.*

Mrs. H.: *"That is one of the things that is beginning to get ironed out isn't it. Last Friday night* (party at Summerton Road) *she didn't want to be the centre of attention."*

Mr. H.: *"Yes, she was lost amongst the crowd on Friday night. She's growing up isn't she? I know, we are absolutely thrilled."*

Mrs. H.: *"One of the things I wanted to say is that I'm delighted in the staff at Summerton Road. I was always very pleased to see a mixture of staff ages, and young members of staff of Catherine's age."*

Mr. H.: *"This has been one of the greatest assets."*

Mrs. H.: *"As well as the older members of staff who can give the mothering. I think that it is a very good thing and I have always been delighted about it. You have the young ones with all the enthusiasm and the knowledge of what they like doing at Catherine's age, and then you get the older ones who say, 'Well, perhaps we want an extra pullover today as it's a bit cold'."*

Mr. H.: *"There's another thing that did please me very much which I would like to mention. I know Catherine's hairdresser quite well. When she first went there he said he chased her round and round, from one chair to another, and did a clip at a time. After about two hours he finally got a bit of hair off. And the last time she went there, he said to me, 'I was amazed that Catherine sat in the chair, never moved, and let me set and restyle her hair completely'. The hairdresser said that he had never seen such a change in a person. The day she came in here with her hair permed we could have jumped for joy, couldn't we? She looked lovely. We never thought it was possible. So, all these little things that keep coming to mind are the things that have given us so much pleasure, the things that we thought could never possibly happen; and they are happening. They keep coming to mind — all these little things such as hair . . . make-up. She comes home with eye shadow and rouge, and she looks like a filmstar sometimes."*

Mrs. H.: *"And they are all so expert at putting it on, I'm not so expert at doing it."*

Mr. H.: *"And the most important thing is her clothes. She started off with that old suit that she used to wear, strapped up at the back; but still she used to fight her way out of it. Now she comes home in the most beautiful clothes and looks very smart."*

Mrs. H.: *"I was very pleased with the last pair of jeans, with the belt — I've never been able to get a belt on Catherine."*

Mr. H.: *"She looks lovely in some of the jumpers and blouses she wears. But before, she never looked lovely. You could almost say she was ugly — fat; and that blue suit, it made her look awful, didn't it?*

Mrs. H.: *"She has lovely eyes."*