

## CHAPTER 5

**Carol Brown — developing independence in familiar surroundings**

Carol Brown had lived in Merton for most of her life. Well into middle-age she lived at home, at first with both parents and then, after the death of her father, with her mother alone. However, immediately before moving to 10 Summerton Road, Carol had been living in a residential facility in a town some thirty miles away, towards the other end of the same health district. She had gone there when her mother had become senile and was in need of care herself. Admission to residential care is frequently the only service response when the supporting arrangements for a person with a mental handicap living in the community break down. This, coupled with a lack of suitable services locally, meant that the best that could be offered Carol was a transfer away from her familiar surroundings to a new life in a strange setting.

This kind of enforced move, away from home and familiar locality, cannot be an unusual occurrence. It must be true for most people admitted to large residential institutions. Carol might well be considered to have fared rather better than most. She did not go to the mental handicap hospital which officially served her town, which was some seven or eight miles further away, but to a relatively new, small, purpose-built, community-based hostel. It had been provided in the mid-1970's, the time when the care in the community policy was beginning to be introduced. It was intended to serve the town in which it was located. Carol's admission contravened its catchment area policy, but was sanctioned as an emergency, short-term measure. When her mother died, however, Carol became a permanent resident and ended up staying there for three years.

Three years is not a short time, but for Carol, a person with a mental handicap living in residential care, the chance to return to her home town so soon must be considered unusual and a matter of good fortune. Development of local residential services for people with mental handicaps has been slow; many people never have the opportunity to move from their existing residential placements. There is also a view that new local services should be used primarily for people in need who are already living in the

locality rather than for bringing back people who have had to move away. This proposition tends to grow in strength the longer an individual has been in residential care elsewhere. As the deaths of their close relatives occur, residents of centralised facilities lose their connections to localities and become regarded as stateless. Developing services need a fair way of deciding for whom they are responsible and for whom they are not. This is important if the geographic, uneven distribution of resources in the current institution-based service is not to be repeated. Eligibility for 10 Summerton Road was determined by the address of individuals' next-of-kin. Carol was considered eligible by virtue of the address of her brother, who became her next-of-kin when her mother died. She was lucky that he still lived near to the old family address. Otherwise she may never have returned to Merton.

Until there are comprehensive and adequate local services to meet the needs of people with mental handicaps, dislocation of individuals from their familiar surroundings is likely to continue to occur whenever their family or other personal support in the community breaks down. It is some indication of the dependency of such individuals on others and the limitations of present-day services that, when hospital admission was required for her mother, Carol too had to assume the same status. Her mother was old, and in time died. Carol was not old; but departure from her home town had some similarity to death — it was equally sudden and unplanned and could easily have been just as final. After her return, casual acquaintances who knew Carol during the period when she lived with her mother greeted her with statements akin to, "My God, I thought you had died".

It is of course true that citizens do choose to uproot themselves and move periodically. But this fact should not be equated with, and used to excuse, an enforced move necessitated by service inadequacy. Ordinary citizens in general find it relatively easy to re-establish in their new surroundings the kind of casual acquaintanceships they had previously, but this should not lead to the view that the same will be true of someone with a severe mental handicap. The local contacts which Carol has now stem from a time when she was part of a family group, sharing and inheriting the goodwill generated towards the family as a whole. It would be quite a different proposition for her to establish a similar range of contacts elsewhere, independent of family members and absolutely in her own right.

## Personal characteristics

Although Carol was admitted to residential care when her family support arrangements broke down, it would be wrong to view her as being totally dependent on others. In areas of her own care she was fairly self-reliant: eating with a knife and fork, fully ambulant, taking herself to the toilet, and washing her face and hands. She could also dress herself fairly well and had some well-formed, clearly articulated, spoken language. Just before her admission to residential care, it is likely that Carol was contributing as much as her mother to their mutual ability to look after themselves. Her language is a considerable asset. Occasionally she has interactions which appear to demonstrate a sophisticated understanding of the world and which follow appropriate social manners. While at the cinema recently, for example, during the intermission Carol and a member of staff were talking about whether or not to queue for ice-creams. A man in the row behind returned from going to the foyer to buy a hot-dog. Carol turned as he approached and said cheerily, "That looks good, how much are they charging for them?". The man told her the price, at which Carol said, "Yeah, it's a rip-off isn't it?". The man agreed, smiled, and resumed his seat while Carol turned back to talk to her companion. The view of the staff member was that it was unlikely that the man realised he had just had a casual conversation with someone with a severe mental handicap.

However, Carol is correctly regarded as someone in the mid-range of the category defined by the term severe mental handicap; she had an assessed mental age of 48 months. In order to convey an accurate picture of her need for support it is necessary to give an accurate picture of her comprehension and use of language. Her capabilities made her just eligible to attend the main workshop of the local adult training centre. Her language ability needs careful evaluation: to some extent it is illusory; the standard of syntax and delivery not being matched by the content and meaning. Her speech is often a collection of short, disjointed phrases and the information it contains is often inaccurate. She finds it difficult to answer questions meaningfully. Conversations often involve repetitive, "cocktail" chatter, based more on formula and social convention than actual comprehension. She is someone who has great personal strengths of enthusiasm, kindness, and sociability. She is also someone for whom it is difficult to encapsulate the

precise nature of her handicap and therefore determine the best course of action in order to help her.

The changes in Carol's life on moving to 10 Summerton Road cannot be described in such dramatic terms as those for Shirley, Catherine, or Mary. Nor do they involve such tangible issues. For instance, she did not have a major disruptive behaviour to be coped with, she has not had a job since moving, she did not move from an obviously deprived place of care. Her skills have developed to some extent since moving, but such development is relatively insignificant. The greatest change has been in the breadth of application of the skills she does possess and in the independence with which she leads her life; the flowering of an adult life style.

We hope this feeling of growing maturity and adult independence will come out of our account of Carol's experience of the service. We have had difficulty in striking the right note, given the enigmatic quality of her abilities and handicap. Progress in some areas has been slow. In others advances have been rapid but, even so, we do not wish to represent her development as being less of a challenge to service programming than it has been. Indeed, the most common error we have made in assessing Carol's needs and devising the day-to-day service contribution appropriate to them has been to overemphasise her ability. In particular, we have often misjudged her ability to comprehend complex language, to carry out anything other than simple, one-step instructions, or to keep concentrating on something without frequent support or interest being shown in what she is doing. This is not a criticism of Carol but a representation of the difficulties that we, the service providers, have experienced.

### **Before moving back**

Carol had been admitted to a 25-place facility situated on the corner of a geriatric hospital site on the outskirts of a town. It was a modern building which, apart from its size, was designed to emulate a domestic situation. Bedrooms were single or shared (up to three beds per room), many with washbasins set between the built-in cupboards and wardrobes. There were two living rooms, a large dining room, a hobbies room, and a kitchen (although this had not been fully equipped and meals were supplied from the neighbouring hospital). The unit was comfortably furnished and carpeted and in good decorative order.

It was a difficult time for Carol. She had experienced a major change in her life, possibly with little preparation. She took a long time to settle. She had, and still has, a tendency towards immature social behaviour: making crying noises, being overly apologetic, and sometimes mildly biting her forearm when corrected, however gently or pleasantly. She sought attention and demanded physical contact by asking to be cuddled. She did not want to go on trips out during the first three or four months, although this later became a favourite activity.

One of Carol's great strengths is that she offers her friendship easily and trusts those who respond in kind. She has great sociability and cheerfulness. Although sometimes annoying in her desire for attention, she is so outgoing and pleasant that she is generally well-liked. She is without malice; caring and friendly towards the other people with whom she lives. Staff in the residential unit had described her as having a strong maternal attitude towards one woman, who had a profound and multiple handicap, whom she used to help feed, dress, and otherwise look after. She had also taken a special interest in one younger man who was learning a sign language. She spent much time with him, helping him to practise signing.

Carol's self-help skills were described earlier. She could feed herself neatly and well, she could dress independently even to the extent of putting on appropriate clothes for differing weather conditions, although she needed help with choice of clothes and fashion sense. She needed supervision during bathing and reminders in the morning to brush her hair and teeth. She used to go shopping in town with staff. However, because catering was done elsewhere and many other consumable goods came *via* hospital supplies, there were few opportunities to do so for anything other than personal clothing and toiletries. She had a variety of recreational interests. She liked television and music, and enjoyed dancing and going out to the pub. She also liked physical activities and would join in a game of football played on the back lawn and look forward to the trips to sports and amenity centres which were organised. She attended the local adult training centre during the day.

Other means of occupying her time were relatively limited. The unit maintained some emphasis on residents doing domestic activities which directly concerned them, such as tidying their own rooms; an emphasis that was perhaps greater than would typically

be found in a hospital ward. However, the involvement of central catering and laundry services and a full domestic staff meant that Carol had fewer opportunities at the residential unit than she would later experience in her new home. She was involved in tidying, dusting, and polishing her room but she needed much prompting and had a very short attention span. Staff found that she needed constant supervision and attention to keep going. Without this she was likely to stop doing the required task and wait for staff to return, perhaps hovering one spot over and over or standing holding the tin of polish or looking out of the window. She was involved in a cookery class, but although she appeared to have an intellectual appreciation of what to do she had little practical competence. For example, she knew that a tin-opener was used to open a tin, but she could not do this herself.

Concentration was a continual problem in getting Carol to achieve any level of independence. She could set a table for dinner but needed constant instruction, not only about what to do but also to stick at the job. It was often at these times that her immaturity showed most. She would constantly seek approval: “Carol did well, didn’t she?”; “Carol’s clever”; and she would respond to helpful instruction by crying or other anxious behaviours which she would then correct herself by saying, “Don’t be silly, Carol”. She enjoyed going to the pub but staff often found her embarrassing company so these visits were to some extent restricted. While out she would again show immature and mildly inappropriate social behaviour, laughing hysterically at no cause, repeatedly apologising, and making crying, anxious noises.

Carol’s appearance at this time underwent some change. She had arrived at the residential unit with what staff described as a rather old-fashioned, “frumpy” appearance. She was quite portly and had a wardrobe of dresses which were mainly shapeless shifts of printed cotton, some long, pleated tweed skirts, and a number of cardigans and blouses, all rather dull in colour. She had a plain hairstyle; straight, shoulder-length, and centre-parted. She lost weight after arrival because, perhaps in her distress, she was choosy about her food. Staff made a conscious effort to introduce more shape to her clothing, to style her hair, and to make her look younger. Subsequently, she began to eat well and regained weight but she kept the younger style.

Staff at the unit cannot recall Carol having any family contact herself, although there were discussions between the staff and

Carol's brother once he became her next-of-kin concerning arrangements for the disposition of their mother's property. Carol inherited a substantial sum in her mother's will and an order was made to place her under the guardianship of the Director of Social Services. However, despite being personally wealthy, she had few possessions of her own at the time. Her money only started to be used more extensively for her own welfare after she moved to 10 Summerton Road.

When the opportunity came for Carol to move back to Merton, the senior staff of the residential unit were not enthusiastic. They advised against moving her again in view of the length of time it had taken for her to settle. Carol was consulted, but her tendency to respond to any question by crying coupled with the unreliability of her statements made it very difficult to interpret what her wishes were. As with Shirley, her own preference could not be properly established. Under these circumstances there were some fears about the wisdom of the transfer; but when the move was finally made, predictions of difficulty proved groundless. Carol was happy to return to her home town and she moved into her new home, with its unfamiliar surroundings and staff, without batting an eyelid.

### **Developing independence and perseverance**

Carol moved to 10 Summerton Road during the second week of November, 1981. The description we had been given of her and the way she behaved in her previous home was confirmed by the initial experience in the house. Her speech gave the impression of greater understanding than she had. Carol could follow simple directions but certainly not those which involved two or more parts. For example, if she were asked to get out a mug and a spoon she would do one or the other, but not both. She did not listen to what people said to her, spending her time instead nodding her head and saying "yes", or making anxious noises, or otherwise answering. Although the impression of the social interaction seemed normal, it lacked function. Even immediately after a conversation Carol would often be unable to do what she had been asked or to repeat what she had been told.

Her dressing skills needed some refinement. She could not fasten the clasps on her bra or tie shoe laces and she tended to pull off her buttons and to enlarge button holes when undressing. Attention-seeking, involving immature social overtures, was

frequent and Carol has shown bouts of mild self-injury when demands have been made of her: biting her arm or lightly slapping her face. She could not be given the responsibility for completing an activity and staff support to lengthen her concentration and perseverance had to be carefully programmed. She also had a habit of collecting and hoarding rubbish (ribbons, pieces of paper, and other small items) and she smoked heavily, pestering others for cigarettes as well as smoking her own.

Carol came to Summerton Road at the same time as Shirley, Catherine, and Mary. She neither presented such conspicuous problems as them nor, compared with Shirley and Mary, had she suffered such neglect. She was the most able, least disruptive, person then living in the house and in the first few months her needs were perhaps made subordinate to those of the others in terms of receiving staff attention. Some things were done for her, but the intensity of effort was missing. Carol had previously held an adult training centre place elsewhere in the county and an application to go to a similar form of day provision was made. She gained a place within the first six months and the main elements of her daily and weekly round resumed a fairly familiar pattern. At one time Carol had smoked heavily but while at the residential unit this had been reduced from up to sixty cigarettes a day to less than five, and then to a couple. This had led to a tendency for her to ask for or otherwise scrounge cigarettes from others. After moving to Summerton Road, she increased her smoking out of personal choice and grew used to offering and accepting offers of cigarettes with staff who smoked. Care was taken that her smoking stayed within reasonable bounds — about ten a day.

Carol now is a smart and presentable woman in late middle-age. She is slim (for her age), has good, well-styled hair, and an attractive face and figure. She has no observable physical signs of handicap, awkwardness of movement, or peculiar mannerisms. Some conscious changes in her appearance have been made since Carol first moved in. The attempt to change her “old fashioned” appearance which had been made in her previous place of care had resulted in an appearance more suited to a juvenile than an up-to-date adult. Immature appearance is common among adults with mental handicaps and it can have the effect of accentuating their intellectual disability through the sense of childishness and lack of responsibility it conveys. This was particularly unfortunate for Carol who, despite a beneficial physical appearance, was in



danger of being seen as genuinely immature because of her social behaviour. The need for her to develop a more mature bearing and physical appearance, as well as improved social behaviour, were soon identified as prime objectives.

In common with the other people moving to the house, a process of purchasing new clothes, adult shoes, and jewellery, of having new and changing hairstyles, and of experimenting with make-up and other cosmetics to enhance appearance was begun. Carol had the added advantage of personal wealth held under the guardianship arrangement. In order to buy clothes and other possessions, negotiations were conducted on Carol's behalf so that she could have greater access to her money. She began to receive a regular income with occasional larger amounts for expenditure on consumer durables. After eighteen months, the guardianship arrangements were relinquished and her money is now held in trust. This provides appropriate controls while easing the practicalities of gaining access to her income. Carol has her own Post Office account which she uses both to finance day-to-day requirements and to save for items involving more substantial expenditure. As a consequence she now has a large wardrobe of both work-a-day and high quality clothes. Probably of all the people who live in the house, she is the only one who could be described as possessing a wardrobe of clothes suitable for all of the normal range of social functions that a successful working member of the community might attend. She can dress suitably for the theatre or for a London show or to go to church; events which she attends regularly as part of the community life style of a person with resources.

The rearrangement of her financial matters has altered Carol's status of having few possessions. She now owns a range of material goods from which she can derive pleasure. Her spending, following staff recommendations on her behalf, is certainly not profligate. She has bought a television and some stereo equipment for her own room, she has been able to change some of her room furnishings so that they are more to her taste, her choice of holiday is generally less constrained than it is for her companions, and she is able to go to a wider range of cultural events as she can afford the cost of travel away from Merton more often than others with a lesser income.

The objective of developing a social demeanour appropriate to a smart woman in her fifties has been a more complex matter to

attain. Teaching and changing behaviour is more difficult than buying new clothes! But progress to the current position can be traced back to the first weeks in the house. Carol was encouraged to participate more in her own care and in activities about the house. She was also encouraged to be more reserved in social manners, differentiating friends from strangers in the style of greeting, and desisting from intimate hugging or kissing. (The frequency of contact from relatives has remained low and there are few people in Carol's life for whom such intimate interactions are appropriate.) Another objective was to reduce the crying, overly apologetic, sometimes self-injurious, or otherwise immature or inappropriate reactions to requests, correction, or criticism. In using the word correction here, we are not talking about punishment. We mean help and support to do something correctly and successfully. An inability to accept the help and advice of others is a considerable barrier to achieving a more normal social existence and developing independence.

The other side of the coin was for Carol not only to develop new skills but also to use the ones she possessed to gain more independent control over her activities. If she could develop perseverance in tasks she could do, and take initiatives that would lead to genuine accomplishment, her contribution would naturally generate the social recognition she so obviously wanted. Participation and accomplishment were seen as more constructive, alternative ways of gaining staff attention than the immature and anxious behaviours she displayed. These were ambitious, global objectives, and in some respects development has been slow. Sometimes staff effort has had little return; nevertheless, the definition of Carol's major needs has been successful on the whole in giving the service a therapeutic direction which has promoted significant changes in Carol's status, personal confidence, and life style. Although changes in different areas overlap and interact with each other, for ease of description Carol's progress will be described under three headings: her contribution to the household; her independence as a "lady about town"; and her growing social maturity as an adult.

### **Being a contributing household member**

Carol was always one of the most substantial contributors to household life. When working with her staff had the sense that the task of getting something done could be taken at a slightly more

casual level. The change over time is in the quality of how she fulfils her role. She is now considerably more skilled, more mature, and more confident, so she is treated as being more responsible. Her rate of learning has not been as dramatic as Shirley's who, despite her absence of language, has also assumed a particularly responsible position in the household. Nor was it achieved so easily. Carol has an enigmatic quality; an ability to appear to know how to do something because she can respond, in a transient fashion, to requests. But unlike Shirley she has a substantial functional handicap in not being able to perform the mechanics of the tasks she sets out to do. She lacks any sense of standard and she tends to start an activity without being able to carry it through. A consistent mistake in the service staff's response to her has been to overestimate her ability; a mistake which was never in Carol's interests. Experience in the last three years has been of an ultimately rewarding but painstaking job: showing Carol how to do all the everyday range of domestic tasks; giving her instruction and, initially, frequent praise to motivate participation; then gradually reducing the frequency of praise in order to lengthen her concentration and build accomplishment.

Carol, as a result, has learned to make simple meals, to clean, tidy, polish, make drinks, iron clothing, wash up, stack the dishwasher, unpack the shopping and put things away, and do the laundry (with some continuing help and supervision). Her attention to tasks and her perseverance has gradually increased so that she is now able to continue tasks for about twenty minutes or so, quite long enough for the deliberately programmed praise and encouragement to give way to that recognition and social interaction we all get as an incidental consequence of our activity. It would be nice to be able to say that the programme staff followed to gain this development was so precise that what emerged was a gradual but constant growth in competence, desire to join in, and increase in concentration in the classic manner. The truth is a little wider of the mark.

A recurrent mistake has been to misjudge the length of time Carol can continue an activity without encouragement. Often, because of the need to pay attention to a member of the household who is more severely handicapped, by the time attention has been given back to Carol she has either ceased to be engaged in her task or has left it completely to seek out staff in order to gain attention some other way (often by displaying immature social behaviours

or by complaining of aches, pains, or invented injuries). When the balance of staff attention has moved away from being directed at constructive engagement in a meaningful activity, it has invariably shifted to those behaviours which Carol has initiated, presumably because she has found them to bring about long-standing success in gaining attention, namely: complaining, crying, irrational laughter, mild hypochondria and “acting silly.” However, we think it is also true to say that one of the strengths of this residential service has been the sensitivity of its staff to subtle changes in behavioural frequency shown by the people living in the house and their ability to analyse these and adjust their own performance within the structure of the weekly staff meetings. Fluctuating behaviour is not seen as the random variation inherent in the expression of an individual’s underlying personality trait. Instead it is viewed as a possible rational comment by the individual on the prevailing situation. Thus, perhaps in a more faltering fashion than would be ideal, the pattern of staff interaction with Carol has largely met her needs and enabled progress to continue.

Carol now knows how to collect what she needs for a bath, run the bath water, take a bath, wash herself adequately, and dry herself afterwards. She has become consistently competent in self-care after using the toilet. She has learned to brush her hair thoroughly and to maintain her hairstyle, and she is making progress in her ability to wash her hair herself. She now brushes her teeth regularly with an electric toothbrush. Specific teaching has been given for some of the more subtle refinements in dressing and undressing, and attention has been given to detail, such as teaching Carol to wash and dry her hands thoroughly after finishing working in the kitchen.

But more important than the increments in specific skills is Carol’s heightened motivation to engage in activity and contribute to the household. This is beginning to generate a degree of self-initiated activity which, though not as sophisticated as that shown by Shirley, is still to be cherished. It is evidence of a step being taken which provides a degree of optimism for further development. It also reflects a certain quality about the ethos of the house: that the people who live in it feel free to take upon themselves the decision to do something. Carol will initiate the making of a cup of tea or coffee for herself or the household. She likes gardening, has become good at it, and chooses when to go out

and do it. She is becoming reliable at tidying her room in the morning before going to the adult training centre. She initiates cleaning and polishing of the furniture, and doing the laundry. She still needs staff help to carry out the entire sequence of activities involved in performing these tasks, and the standard of cleaning and polishing benefits from staff guidance, but these are relatively minor points. Carol can iron clothes completely independently and will sometimes decide to occupy herself in this way for twenty minutes to half-an-hour at a stretch. She likes shopping and can unpack and put away the goods she has bought.

### **Being a lady about town**

Independence in life has also been developed for Carol in her use of the surrounding community. Carol is sociable in nature, knows her local town well, and is in turn familiar to a considerable number of local inhabitants. She enjoys going to the shops or to activities in the evening. She has no close contacts or substantial friendships other than her brother's family (whom she sees little) and a cousin (whom she refers to as "Aunt") and her husband who live in a town in the neighbouring county. She goes to stay with them about six times a year. Being a fairly active member of a local community, with a network of casual acquaintances, may partially offset the absence of any close relationships and give her a real sense of belonging.

To enhance Carol's ability to benefit from her return to Merton, various specific skills relevant to independent or accompanied use of local community facilities have been taught over the last three years. At her first individual programme planning meeting in 1982 road drill was identified as an area for development, although little concerted effort in this respect was made until a year later. When programming did start, Carol was first taught simply to look for and identify the arrival of the training centre transport at the house in the morning. Later she was taught to halt at a kerb without a reminder, then to decide when to cross side roads, and afterwards how to cross the main road at a place with a central island. She began to catch the town bus to go to the adult training centre instead of using the supplied transport. At first she had staff help, and then some supervision from one of the trainees from the centre which was organised by staff. Involvement of this trainee was not altogether successful and a move to the final step of travelling independently was somewhat accelerated out of

necessity. At this point, when Carol was leaving the house alone to cross the road, go to the bus-stop, and catch the bus, and doing the reverse on return, staff kept a concealed watch to make sure that she had learned the necessary skills to negotiate the journey independently and safely. Once satisfied of this, Carol has been able to travel unaided.

Apart from crossing roads and using a bus, other teaching for Carol has centred on queuing and turn-taking in shops and in the Post Office where she has her account, holding shop doors open for the convenience of others, closing a car door after getting out without a reminder, and using a seat-belt also without a reminder. Although not good at money she can now name some coins and can use the closest shops (a greengrocers and a newsagents) independently, either taking a list and sufficient money for household shopping or asking the assistant and managing payment herself for specific items such as cigarettes. In a supermarket she can find goods on request provided only one instruction is given at a time. She has also learned to order drinks in a pub.

These skills are adding a considerable dimension to Carol's life of independent action outside the house. The safe crossing of roads and use of the bus, which had first been achieved for the specific journey to and from the training centre, has generalised to other roads and use of other bus-stops. For example, rather than always getting off at the stop nearest the house when returning from the training centre, Carol may choose to travel directly to town to look around the shops, and to walk home afterwards. Moreover, to complement their growing responsibility for their own safety outside the house, it has recently been decided that Carol and Shirley may be left alone inside the house for short periods. This means that the choice of activity available for all the people who live at 10 Summerton Road is becoming less interdependent and less constrained by staff availability. For Shirley and Carol this development is very similar to what happens when a teenager becomes independent from the requirement to accompany the family every time the household shopping needs to be done or when a younger brother or sister has to be taken to an appointment outside the house.

### **Growing social maturity**

Carol's growing social maturity is essential to her independent use of community facilities. Without it, and the resultant

responsibility she shows for her actions, the independence she is permitted would not be possible. It would be tempting to view this development as a natural by-product of a greater access to the normal adult social world, either through some improvement in self-image, or through direct exposure to competent role models, or through some conditioning process inherent in the reactions of other citizens within the community. Certainly, opportunity to develop is a pre-requisite for development and the opportunity to imitate competent citizens can only help this process. It is also beneficial when other citizens respond appropriately and with understanding to an individual's social overtures. But to attribute change exclusively to such factors would be to ignore the planned and coordinated staff management that has occurred.

Although it can still not be claimed that Carol has the maturity expected of a woman in her fifties, much of her immature social behaviour has lessened in frequency and intensity, to the extent that it is now rare. For example, she now has perfectly passable social behaviour in a pub: she can sit and converse in a discreet enough manner, she can order drinks, she can take turns, she can play fruit machines without direct guidance and without making a silly pretence of hopelessness. She can go to the cinema (accompanied) and behave in a way which causes no concern and is completely acceptable to other members of the audience. She is able to go to concerts and on other trips out. Her demeanour within the house is similarly improved.

In developing her social abilities, staff have always had an advantageous starting point in terms of Carol's inherent sociability, cheerfulness, cooperativeness, and desire to please. What needed to be changed was the way in which she attracted the attentions of others, from one which portrayed her as a somewhat embarrassing spectacle, playing on characteristics associated with handicap and immaturity, to one which emphasised her competence and achievement. Her ability to accomplish worthwhile tasks in the house, which was fostered by teaching her new skills and greater perseverance by means of a mixture of staff instruction and deliberate attention to worthwhile activity, was the general backdrop to changes in her interpersonal behaviour. Over-intimate greeting, hugging, and kissing was discouraged in much the same way as it had been for the much more extreme form shown by Mary. Reduction of false crying and invention of complaints was achieved by encouraging her to persevere with

alternative forms of occupation and by giving her due recognition when she followed instructions and engaged in worthwhile activity. At the same time staff simply asked Carol not to cry, complain, or “act silly,” and not to apologise repeatedly following correction. If she persisted, they ignored her.

Progress was not uniformly good; there were periodic setbacks. The most significant occurred after about two years in the house when Carol began to show an increasing frequency of mildly self-injurious behaviour which took the form of biting her forearm and slapping her face. Staff collected information on its frequency, the antecedents to the behaviour, and the consequences that followed. The data indicated that Carol injured herself when staff asked her to do things, despite the fact that they usually continued to require her to do what they had asked and ensured that she did so. Probably two factors were associated with the behaviour. First, the self-injury deflected the demand for a few seconds, thus delaying the need to make a response. Second, it probably had the effect on staff of offering Carol more help when they repeated their request. The recurrent problem of over-rating Carol’s abilities and expecting too much of her had been found again.

The response to this episode was finally a good one, both for the specific problem and for Carol’s social behaviour in general. It seemed to mark a real breakthrough in her developing maturity and a change in the relationship between Carol and the staff. Carol was taught to ask for help. For incidents of hitting herself, complaining, “acting silly,” or crying, she was given a short reprimand and then instructed to say, “Can you help me please?”, or words to that effect. Staff persistence with teaching her to ask for help in an adult manner was successful. Carol’s more immature forms of avoiding demands or gaining help started to lessen and she grew in status in the eyes of the staff.

### **A woman about the house**

As Carol has grown more mature in her manner, it is possible to trace changes in the relationship between her and the staff. There has been a greater relaxation in the style of interaction which is now closer to that of a peer-group friendship than before. As has been said, her more mature status is reflected in the decision that she can be left with Shirley in the house unsupervised. She can take decisions on her own initiative. One story concerns an incoming telephone call. After dinner, the telephone rang when



staff and some of the household were washing-up in the kitchen and Carol was clearing the dining room. Carol called, "I'll go" and answered the 'phone. Staff heard the typical listener's response of a periodic "Yes", "Uh, hum", and then Carol said, "I'll get her" and put the receiver down beside the 'phone. Carol found Linda (another member of the household) and said, "Phone, it's for you", and Linda went to the 'phone to take a call from her mother. The entire episode was appropriately conducted without any staff intervention. It illustrates how people living in the house can assume increasing responsibility in their own home environment.

Carol has little contact from relatives; maybe one or two visits a year from her brother's family. Mollie (her cousin who looked after Carol's mother during her later years) and her husband Ken invite Carol to stay with them for the week-end every other month or so. But otherwise Carol's life is based essentially within her house and in her town. She did develop a friendship at the adult training centre with a woman of about her own age who lives in a hostel some twelve miles distant and invited her to stay at the house overnight on several occasions, but that friendship has since declined. Within the house, Carol has moved from having her own room to sharing with Kathleen, who moved in two years after her. Kath, as she likes to be called, is a bit younger, attends the training centre and, until about a year ago, lived at home with her mother. Kath had previously spent several short stays at the house and objectives had been set in both women's individual programme planning meetings which would foster their friendship for their mutual benefit; Carol being rather short of close contacts, and Kath being rather isolated at home from any involvement in the local community, particularly in the evening. When Carol went to the cinema or a concert locally (accompanied by staff), she began to call for Kath on the way. After Kath moved to the house, Carol chose to share a double room with her.

Carol has the kind of daily and weekly routine that adults in ordinary families look forward to having after their children have grown up. On weekdays she has to get up at about 7.30 am to get ready to go to work (at the training centre). She likes to have breakfast TV on as she wakes up, washes (there is a vanitory unit in her bedroom), and gets dressed. At weekends she gets up later, between 9.00 and 10.00 am., and likes to watch TV in bed. She usually goes to bed about midnight, although she can go earlier if she feels tired. On Friday and Saturday evenings she might watch

the late film. When cleaning and tidying her room, or when changing to go out in the evening, she often listens to the radio, a record, or a tape. At other times she might not choose to watch TV or listen to her stereo in her own room, preferring to be part of the social group in the house. In the evenings she might go to a pub or to the cinema, or she may decide to stay in and have a bath. Sometimes she may need to attend to housework or take her share in doing the main shopping for the household. (This is usually done at a supermarket which stays open late on some evenings during the week.) She is a keen gardener and has taken on the front garden as her own to tend and develop.

Throughout more than three years at the house, the individual programme planning approach has ensured that staff regularly review their thinking about what is best for Carol's welfare. Attention has been paid to some very specific things: teaching her to sit in a skirt with her knees close together rather than sprawled apart, particularly when out at the pub; and teaching her how to use her television and music centre without any help. Other things have been more general: concerned with her health, appearance, and role in society. For example, Carol and a member of staff regularly attend an evening keep-fit class run for the general public. Recently Carol has had partial dentures to fill the gaps between her natural teeth and these have been a great success. Although she initially said she would not wear them she now willingly uses them all the time.

One major issue for the future is for Carol to obtain a more productive and rewarding working life. As the burden on staff time from supporting Shirley in her job eases (see Chapter 2), it may be possible to carry out a similar exercise for Carol. Staff may be able to establish a similar co-worker arrangement, but in a different type of job — one which is more suitable for someone with a sociable personality like Carol's — and then gradually to withdraw their support after having taught Carol independent competence. There is a possibility that Carol will be a productive wage earner before she reaches retirement age.

Although her family is not a close one, Carol is still part of it. Both her cousin and her brother have been impressed by the changes that have occurred, in particular the growth of Carol's sense of self-reliance, responsibility, and social maturity. Carol now has her name on the council house waiting list. Who knows what the future might bring?