CHAPTER 2

Shirley White — a new home and out to work

Shirley White moved from a large mental handicap hospital to 10 Summerton Road, Merton on Sunday November 1, 1981. It was the beginning of a considerably improved life, which brought her back near her father and two sisters who had kept in touch with her throughout the thirty-five years she had spent away. Shirley had lived in hospital since the age of six. For almost thirty years she had lived in the "locked" ward for female "patients". When she moved she was nearly forty-one years old. When first arriving as a child, her new home was still officially called a "colony". A year later, following the formation of the National Health Service, the colony became a hospital which, during the next three decades, saw the development of the mental handicap nursing profession, a greater proliferation of psychiatrists, and the growth of psychological and paramedical involvement.

Shirley's home, which she shared with more than thirty other women, was a two-storey hospital villa, a detached ward set among others in a country estate. On the ground floor was one large living area and dining room. Upstairs was a large dormitory in which Shirley had a bed and a small bedside locker. In this she kept her clothes and a few personal possessions such as her dolls. There was only one dormitory, and to this day it is not partitioned to give any privacy. There were some small side-rooms which were used to isolate people who were "very difficult". Many of the people who lived in the locked ward had disturbed behaviour, including Shirley herself. It was the female "back" ward, into which women who had been hard to manage elsewhere in the hospital had been collected. People living in it were detached; many showed bizarre patterns of behaviour. It is difficult to imagine how staff could avoid being overwhelmed by their task of trying to create a normal social environment and a normal daily round of purposeful occupation. Here was a situation in which people who had particular difficulties in relating one to another had been deliberately grouped together.

Shirley is profoundly deaf. She is also blind in one eye and poorly sighted in the other. Her notes record an estimated

intelligence quotient of approximately 20, but this is hard to accept given Shirley as we now know her. She was fully ambulant, had good motor control of all limbs, could take herself to the toilet, feed herself, and could wash and dress herself independently to the standards required in hospital. However she had no means of communication at all, being mute unless in a state of extreme agitation and having been taught no form of signing or symbolic language.

In an unsympathetic social setting, with no means of communication, unable to hear, and with limited sight, she naturally had difficulties in filling her day constructively. Although competent in her own basic self-care, she had no hobby skills, no work, and no ability to converse with which to occupy the intervals between getting up, mealtimes, and going to bed. The environment in which she lived emphasised rather than alleviated her personal handicaps. Social isolation, peculiar behaviour, and lack of meaningful activity were usual. In order to establish simple basic opportunities for people living on the ward special arrangements had to be made. Even then, they could affect the lives of only a few. Just before she moved, a change in ward organisation had allowed Shirley and three other women to eat their meals separately from the others and help to wash up afterwards.

Although the villa was called a "locked" ward, this did not mean that the women were denied access to the hospital grounds. Indeed it is hard to be precise about the exact meaning of the designation "locked", or what purpose the emphasis on security served. The clearest practical effect was to create the "back" ward identity and the grouping together of people considered to be mentally ill as well as mentally handicapped. At the time of her leaving, Shirley's main and favourite activity was wheeling a small doll's pram around the hospital grounds. She was not considered likely to stray off the hospital campus. In fact, it was said that she clung to the hospital as her source of security. It was confidently predicted that Shirley would become distressed and extremely agitated if taken outside the hospital. For this reason, she had not been included in recreational outings or taken on trips to the local community. Nor, on the advice of staff, did her relatives do anything other than visit her within the hospital.

With no organised daytime activity Shirley spent much of her time walking in the hospital grounds. When in the ward, she

passed her day in self-stimulatory, rhythmic body- and head-rocking, and walking in small circles. Her notes make it clear that this was her characteristic activity. The emptiness of her hospital life was dramatically illustrated to us shortly after she had moved. Shirley made a curious sign with her fingers. It involved holding one palm flat in front of her and tracing round and round it in circles with a finger of her other hand. As Shirley appeared to use no form of communication, it was thought important to investigate every gesture as having possible meaning. Staff at 10 Summerton Road telephoned the ward staff to ask their opinion. They too had noticed this curious behaviour but said that they did not know what it meant, other than possibly signalling an intent to walk round in circles. This reply gave a powerful image of the long-term nature of the setting in which Shirley had lived. It produced a strong impression of the poverty of the institutional environment where such a behaviour could be a dominant preference. Worse still, it showed the kind of activity that is considered reasonable in such settings and is tolerated for months and years.

Part of the reason why Shirley lived where she did was that she was very disruptive. She injured herself and was aggressive to others. Periodically, she hit her head and attacked her face near her eyes. During the day she sometimes hit other women who approached her. At night, she had outbursts of attacking others and tipping them out of bed. Although records of this disturbed behaviour are frequent in her notes, there was no specific programme of management. All that was noted was an assessment of the severity of the problem, which varied from entry to entry. At the time of initial discussion as to whom 10 Summerton Road might serve, a psychological report on Shirley's behaviour suggested that the problems had lessened. It attributed the improvement to the fact that Shirley had been given a new doll's pram to push round the hospital grounds. However, a few months later the severity of her disturbed behaviour returned, consistent not only with a possible decline in pleasure derived from her new pram but also with the long-term picture of fluctuation given in the notes. Shirley was prescribed a regular tranquilliser, with back-up dosages of a second tranquilliser and a sedative to be used as required.

Apart from such medication and the care of the ward staff, there was little evidence of attempts to help Shirley live a more full or satisfying life. There is no record of any assessment of either

hearing or sight during her thirty-year stay in hospital, despite considerable sensory handicaps. Her deafness is, in fact, irremediable. Her poor eye-sight, however, had received surgical treatment in early childhood. Her father remembers her having a number of operations when she was an infant and the opthalmologist who assessed her after the move to 10 Summerton Road confirmed the presence of operative scar tissue in her eyes. As a young child she had glasses which her father says she took with her on admission to hospital. Sometime during her years there they were lost; and Shirley came to 10 Summerton Road without this simple aid to alleviate her conspicuous impairment. Even with glasses, which she was prescribed in the second month after moving to her new home, her eyesight is poor. Nevertheless, they have made a considerable difference to the precision with which she can conduct her life. For example, if Shirley wished to pick up a moderately-sized object such as a salt-cellar, without her glasses, she would pat the surface of the table with fingers outstretched until they made contact with it. Wearing glasses, she can pick up the object deftly in one go.

Throughout her time in hospital, Shirley's father and two sisters visited her regularly. It was a seventy- to eighty-mile round trip, so they could only manage to visit monthly. Shirley shows a strong affection for her family, and her family for her, as is obvious to anyone seeing them together. While she was in hospital, her family visited her in the ward. Believing that Shirley did not wish to leave the hospital they confined any trips out together to the hospital grounds. This widely-held opinion cast doubt upon whether Shirley would like to move to 10 Summerton Road. It also gave cause for concern about whether the forty-mile journey could be achieved safely and pleasantly.

Making the transfer: moving to a new house

There are at least two perspectives on the benefits of an alternative service such as the one proposed in this book for a person in Shirley's situation. There is the view of the staff who have worked to establish the home, who have held to their task in the face of the claims and counter claims of supporters and detractors of the new venture. They possess a genuine expectation that the quality of life of people receiving the new service will be enhanced by moving. Their commitment implies a belief that such a service would be good for anyone in Shirley's situation. But

there is also the individual's perspective. For Shirley the move involved changing one home, of thirty years' standing, for another. What is there to suggest the general arguments are correct in every individual case?

As far as Shirley is concerned the evidence appeared to point to a preference for staying in hospital. She was said to view the confines of the hospital campus as a major part of her own personal security; an opinion which, stated in general terms, conforms closely to the notion that hospitals provide a genuine asylum for people who are dependent, who would be unsettled by the demands of the outside world. Shirley's favourite activity was wheeling a doll's pram around the extensive hospital grounds. So favoured was this activity that the purchase of a new pram was linked by a psychologist to a general mood change that brought about a temporary reduction in disruptive behaviour. When considering people for the move to 10 Summerton Road it was not at all clear how this issue would be handled; but it was fairly obvious that Shirley would not be able to push her pram in the same manner around the streets of Merton. Moreover, the garden of an ordinary house would hardly provide the same scope or exercise. Yet, balancing these considerations was a strong sense of the futility of Shirley's current way of life.

It was knowledge of the lives led by people like Shirley which had convinced us that a more meaningful existence should be created for them. Moreover, it was our belief, and this has been confirmed by our experience of working with Shirley and the other adults who have lived in the house, that it is too constraining to judge individuals' possible preferences for the future by their choice of activity in their current situation, or as it reflects their past development.

Of course Shirley's relatives were consulted. They were not members of any local voluntary society and were not actively involved either in support for service change or in defence of existing large hospitals. They were able to hear the proposal that Shirley move to a home near them without hostility and without immediately considering the notion impossible or absurd. (This was not always the case with families. We soon discovered that it was necessary to decide whose rights the service must support; for what appears to us to be in a person's best interests may not always correspond with the views of family members.) Shirley's relatives felt that her happiness should be the determining factor in the

decision. They were worried that, as she had lived in hospital for so long, she might find any change unsettling. They, however, viewed themselves as ill-informed to make a judgement on the alternatives available for Shirley and, probably over-generously, credited us as being the "experts" and left the decision to us.

We were confident that in the long-term Shirley would benefit from moving to a better home; but we had qualms about the first few weeks. These qualms were natural but probably unnecessary. Throughout our involvement in first setting up larger community-based units, and then small homes like 10 Summerton Road, noticeably negative reactions to leaving a large hospital by people with severe and profound mental handicaps have been rare. On the other hand, there have been several expressions of positive preference for the new situation. Given the views of Shirley's relatives and the staff at the hospital, an offer of a trial period in 10 Summerton Road was made, with the opportunity of a transfer back to the large hospital should she seem particularly unhappy after moving. This offer was made with every intent that members of the service team would act as advocates for the welfare of Shirley herself; but there were bureaucratic constraints which meant that a return might not have been possible. The hospital in which Shirley lived was in a health district which was keen to limit its service to citizens from within its own boundaries. Once an alternative residential place was offered for a resident from another health district, readmission was not guaranteed. Three years later, the health district concerned decided to close the hospital in which Shirley had lived. Knowing at the time the direction in which its policy was going, we were aware that some change in her residential circumstances was likely to occur at some point anyway. Shirley was without doubt a victim of the "geographic chaos" of the large hospital system. If she had to move, it seemed to us that 10 Summerton Road was the best option.

The decision, of course, could not be ours alone. We felt we must consult Shirley herself as the client; the person who is the reason for the service. It should never be assumed that people with mental handicaps are incapable of representing a rational view, however handicapped they may be or however low their tested mental age. It would be too glib to suggest that consultation with clients is an alternative to every other form of consideration. People with severe mental handicaps have real problems in

understanding what is said to them and in articulating a view; it is sometimes extremely difficult to know how much they have understood and what significance to give to any answer. There were considerable difficulties in consulting Shirley. She was profoundly deaf, she was mute, she had no recognisable means of communication. As it was believed that she would find leaving the hospital grounds traumatic, the suggestion that she visit 10 Summerton Road a number of times to gauge her reaction before actually moving was not considered feasible. In order to try to explain the situation to her, we made a photograph album of pictures of the new house, some of which had Shirley's relatives in them. We visited Shirley and attempted to tell her as best we could, by gesture and by showing her the photographs, that she could move from the hospital. We gave her the photograph album to keep. We could not tell whether her smiling response was out of enjoyment of the social contact, pleasure from the photographs of her relatives, or whether it represented any form of view about the proposed move. After the visit, ward staff reported that Shirley was proud of the album and liked to show them the pictures. Again it was difficult to interpret whether this indicated pleasure in the possession or at the prospect of moving.

In the event, Shirley moved on Sunday, 1 November 1981. She was collected by a member of the new care staff in a car driven by a parent of one of the other adults who would be moving to the house. A member of the hospital ward staff accompanied her. The predicted stress on leaving the hospital did not occur; the journey was straightforward and uneventful; and Shirley arrived at her new home to find her father and two sisters waiting to greet her.

Early days in 10 Summerton Road

Shirley's family remember her arrival that afternoon:

"We were scared, afraid that Shirley would not settle in. We felt that we shared the responsibility for the decision to offer Shirley the opportunity to move and were worried it would not turn out well. She had been there a long time.

She arrived with a member of staff and a nurse from the hospital. She appeared bewildered and agitated. Although she was wearing new clothes for the occasion, they were ill-fitting but greatly improved on her previous standard of dress. Her shoes didn't fit. She seemed to derive some comfort from seeing us.

She didn't behave the way we thought she would. It must have been strange, it was the first real move in her life. It was different — before she never wanted to go out — she never seemed to — she seemed frightened and gave an impression of insecurity. We were surprised by Shirley on her first day. Her attitude all that day, as I remember, was stubborn. When asked to vacuum the bedroom she did it but I thought there was a real possibility of Beryl (the member of staff) getting the Hoover returned in less than a gentle manner. I had never had a doubt that the move from hospital would be anything but a good one, until then. Shirley accepted what was happening to her, but that was all.

All the clothes we had bought her, she didn't bring any of them with her. We couldn't believe the measly little bag she brought with her from the hospital. Every time we had visited her, we took something from each of us — always a new pair of slippers, a blouse maybe, or a skirt. We never saw them again. What happened to them? None of what she brought with her was what we had bought her. The lovely clothes we bought weren't there. She had on a wool suit which didn't fit very well.

I remember we were hanging curtains with Beryl and the heel came off Beryl's shoe. Shirley's father fixed it. Shirley didn't smile much but I think she settled in well."

There was no immediate prospect of a place for Shirley in the local adult training centre so the opportunities for a changed life style very much centred on the possibilities available in the house and in the town. What is remarkable about Shirley's story is how comprehensively she embraced those possibilities with the support of the staff of the house. Looking back, the course for the future was taking direction even during that first day.

Shirley moved into one of the two double bedrooms in the house, a room which overlooks the front garden and the road which leads to the town centre. The room has a bay window, a washbasin, a fitted carpet, two single divans, two wardrobes, and two chests-of-drawers each with a dressing-table mirror. Shirley unpacked with her sisters' help and arranged her possessions; and in doing so she began her life as an adult with responsibilities, a person who generated household work and therefore could be called upon to contribute to getting it done. The house was not especially arranged for Shirley prior to her arrival. The model was not that of an hotel. During the afternoon she made her own bed, helping to iron the sheets, pillow case, and duvet cover that were

needed. She vacuumed her bedroom and the adjacent landing carpet.

The staff had just completed a two-week induction course. There could have been a view that "the work starts tomorrow". But the work of the staff was, and is, to help the adults lead an ordinary life. Those of us who were involved in setting up the house feel, looking back, that the orientation of the staff was built-up in the induction period and was subsequently reinforced and developed without interruption or exception. With a clear emphasis on resident participation it was important to develop staff skill in helping the people moving in to participate. This is a practical skill which can only be achieved through practice and which has its reward in the increased abilities and contribution of the people for whom they are caring. We cannot be absolutely sure that Shirley used a Hoover and an iron literally for the first time in her life that day, but the introduction of new experiences and opportunities to be involved in everyday events can be said to characterise the contribution of the new service, not only for Shirley but for other people who were to live in the house with her.

Some people may think this approach is too task-oriented and lacking in empathy. In our experience the normal warmth and emotion of human interaction is brought out by sharing in the ordinary things of life. It is when these ordinary things are missing, or when a relationship is not one of sharing and reciprocal contribution, that normal social interactions become distorted and mutual respect is lost. Even on the first day, Shirley needed to be occupied. There was a limit to the length of time that Shirley or her family would want to sit with each other unoccupied; the more so because of a virtual inability to converse or communicate by any means. Everything that has happened since indicates that having the opportunity to join in from the start was acceptable and preferable to Shirley.

We had wondered what we would do about Shirley's favourite activity of pushing her doll's pram. Thankfully, the problem did not arise. Domestic activity became her preferred choice from the moment the handle of the vacuum cleaner was placed in her hand. There was no coercion involved. Shirley's pram and dolls were put in her bedroom and were available for her to use. After some months, during which they were never touched, they were put in the attic storeroom; and some months later they were finally discarded. The operational philosophy of the new service

emphasises the supplanting of childish pursuits, possessions, and personal appearance by others that are appropriate to adulthood, and, more specifically, those which are within the range typical of other citizens of the same chronological age. But such an approach is effected gradually. It should not involve vetoing long-standing preferences, denying people of what little they have. This service did not start by rejecting the possessions the people had, even where the only feasible use of them might have been detrimental to the desired image for the house and for the adults who lived in it.

Shirley had opportunities to learn to prepare food, to do the washing and ironing, to dust, polish and clean, and to go shopping. She had a chance to initiate activities and make choices. Another immediate change in her life was a considerably increased involvement with her family. Whereas before distance had limited contact to seeing her whole family together approximately once a month, she was able to see various members of her family weekly on a regular basis, with additional incidental contact as it arose. She might meet one of her sisters in town when shopping, for example, or one might call in for coffee if passing the house. They might come as guests to a summer evening barbecue. At first, Shirley's family were her only regular visitors but an adult friend of the family started to visit as well and is now Shirley's friend independently. One day a week all the sisters meet for lunch at their father's house, a mile or so from 10 Summerton Road.

Shirley was clearly pleased with the move and there has never been any doubt that she prefers her new situation. She has never shown any desire to return to the hospital. She arrived at 10 Summerton Road with few possessions and little high quality, presentable clothing. Her hair was not styled. She had no spectacles although she had poor sight. None of these things was a direct result of her mental handicap. Indeed, the extent of her handicap makes the responsibility that others had for arranging things better for her quite unambiguous. To some extent, such shortcomings may be related to the personal poverty which people with mental handicaps often experience, but such deficiencies are largely due to neglect.

Within a fortnight of moving, Shirley had been to the hairdresser's, she had bought new shoes and some new clothes, and staff had made appointments for her with an opthalmologist and an audiologist for assessment of her vision and hearing.

Prescription of spectacles considerably improved her ability to see with her good eye. Total deafness was confirmed by the audiologist, but we had not wished to assume this simply from the fact that she came from hospital without a hearing aid.

Shirley had no means of communication. There was a distinct possibility that her sight might worsen and this made the teaching of a sign language a matter of urgency. Another almost immediate occurrence, therefore, was the involvement of a speech therapist to teach staff the *Makaton vocabulary* (Walker, 1980) and to advise them on how to teach it to Shirley. This was the first move in establishing a multidisciplinary group of professional staff who, with the house staff and relatives, would constitute a programme planning team to consider Shirley's needs. A formal system of individual programme planning (Jenkins *et al.*, 1988) was established for every person with a mental handicap living in the house (and for others living at home in the community) by about the sixth month of operation. IPP meetings are held at six-monthly intervals for each person and are a valuable source of guidance for and review of the care programmes carried out in the intervening time.

The rapid development of skills and a new life style

One of the most immediate visible signs of change in Shirley was her appearance. Photographs taken at the time of her move show a person with an expressionless, limp face and tousled hair, dressed in clean but unflattering clothes, whose gaze, without glasses, was almost vacant. Six months later her appearance was dramatically different. The skin and muscle tone of her face were tighter, she was smiling at the camera, her eyes were focused, her hair styled; more becoming clothing and a little jewellery enhanced the overall appearance. During the period which marks her change in appearance, Shirley also learned to iron clothing, vacuum carpets, dust and polish, wash up, rinse the crockery, dry up, and load and unload the dishwasher. Soon afterwards she learned how to use the washing machine and hang out the washing, how to put ironed clothes in the airing cupboard, and how to make good use of her own chest of drawers and wardrobe. She was taught to be more careful in her dressing, personal cleanliness, and bathing. Teaching has also covered food preparation and cooking and Shirley can now prepare and cook simple meals and snacks by herself.

Gradually, Shirley has developed many of the skills needed by adults tending to household needs of themselves or others. However, certain features of group residential life still act to limit the extent to which her experience can be similar to that of citizens who are not handicapped. Living in a larger group than most people, Shirley does not always have to cook, wash-up, and clean on every occasion. Instead there is a need to take turns. The sequence of life and the opportunity to do things is often determined by staff. It can easily seem that the permission of staff is required to do things, and the role of the people living in the house is to be passive until asked. It is, therefore, remarkable, and a tribute to the way in which staff supported Shirley, that she began to initiate activity herself: noticing when things needed doing, taking on the responsibility of doing them, taking decisions, and making choices. One of the first signs of this development was when Shirley collected the coffee cups from the lounge after the evening meal and took them to the kitchen without being asked. A second example was when she went out to the washing hanging in the garden to see whether it was dry enough to be brought in. Other developments involved exercising some control over her own life, like deciding to make a cup of tea for herself, or helping herself to a biscuit or some fruit between meals. She also began to choose what she ate at mealtimes and to communicate to staff when she had run out of things she needed help to buy, such as perfume or talcum powder. Other examples illustrate her contribution to the general upkeep of the house: emptying the pedal bin and changing the bin liner when required; changing the handtowels in bathroom and toilets when dirty. For people who have had long experience of institutional life, such developments do not just represent the gaining of skills. Taking initiatives, without first receiving a request or asking permission, represents a significant movement towards a normal adult life style. For this to grow, the social environment needs to reinforce emerging personal independence. Staff need to embrace the changing status of the "client". They need to find a way of teaching competence without appearing to punish imperfect attempts at independence. For example, there is the question of how to encourage someone to choose what they eat and at the same time keep a healthy, balanced diet and avoid excess.

Changes in the nature of Shirley's social life are more difficult to gauge. She had moved from a social setting characterised by the

presence of a large number of people with strange behaviour, all being left largely to their own devices. She had moved to a smaller setting with a far greater level of structure directed towards encouraging an ordered pattern of life. Smaller rooms allowed greater scope for privacy; but also for collaboration in activity between individuals rather than the entire residential group. This might be expected to offer better opportunities for the development of individual relationships with staff and other people living in the house, as well as more protection from the unwelcome intrusion of others. This, added to the frequent and regular family contact, must provide Shirley with some security in her view of her place in life. Certainly she smiles and laughs; shows affection to the other people living in the house and to members of staff; thanks people for things that they do for her; and recognises changes in others, showing appreciation of their achievements and concern if they are ill or otherwise low. But she has also had aggressive outbursts since moving to the house, sometimes showing annoyance when other adults approach her. Although in a smaller group, Shirley still lives exclusively with other people who are severely or profoundly mentally handicapped; a matter in which she has never been given a choice. Her companions behave at times in apparently aimless, unpurposeful ways. Shirley has always dealt with irritation caused by other people by being aggressive to them. Her hospital notes, covering a thirty-year period, testify to this. She is cut off from the social world by her deafness. Her sign language is still limited. There is, nevertheless, one substantial difference in the small home: a sympathetic and understanding response to her behavioural outbursts, in contrast to the physical restraint and periods of seclusion she experienced in hospital.

A member of the community

Shirley is visited by and visits other people (mainly family) who live in Merton. She is both a consumer and a customer. She goes to a local optician, dentist, and chiropodist. She has a bank account from which she can obtain money by using a card in a cash dispenser. She has begun to become independent outside the house. As someone registered as blind and deaf she has a red and white, striped cane which she carries when going out. At first she was found to be scared of dogs and cats. A programme of controlled and supported exposure to such animals was conducted

over many months, so that she could pass them in the street without panic. She then learned to go to the post box to post letters at the end of the road. More recently, Shirley has been given carefully graduated and supervised opportunities to take herself through the streets of town independently.

Shirley's experience of shopping has developed too. Having rarely before left a hospital campus, and having only seen food coming already cooked and prepared from a central hospital kitchen, Shirley had much to learn. There was a long period in which she was shown elementary facts of shopping, like what goods were in what types of packaging; how to take goods from shelves, use a trolley, and queue at a cash desk; how to unpack and repack goods from trolley to cashier's conveyor belt and then into carrier bags; and how to hand money to the cashier and wait for the change. After months of almost daily practice she has grown in competence and experience. Now she is able to leave the staff member at the supermarket door and purchase a number of goods independently. She uses a specially designed shopping list. Staff put the labels of goods she is to buy inside a plastic wallet. Shirley then collects the goods, matching them to the labels she carries with her. She does not know money values yet, so she is given money that will easily cover the final bill. She hands this to the cashier and collects the change (although she is unable to check it). She also shops with staff for her clothing and other personal requirements.

Shirley also makes use of other services, often going for a drink in a pub or café. She sometimes has opportunities to eat out in a pub or restaurant, mainly with staff and other people from the house, but also with her family on occasions. It is very important that staff have the ability to be flexible in their use of the money budgeted for catering. Just like an ordinary family the people at 10 Summerton Road mainly eat at home but, every now and again, finances stretch to going out. Shirley collects her own pension from the Post Office and, having been taught to write her name, uses her own pension book. In the shopping she does for herself, for the house, and in buying presents for her father and sisters, she is fully involved in making choices. She has learned to sign "for me" for purchases she would like to make for herself.

Having a job

A common problem in developing local, community-based

residential services to replace centralised institutions is that the infrastructure for vocational occupation is not equipped to deal with the influx of people who are brought back to their own localities from distant large hospitals. Soon after people moved in to 10 Summerton Road applications were made for places for them at the local adult training centre, but the length of time taken for individuals to be allocated a social worker, for their application and assessment documents to be processed, and for them to move up the waiting list meant that there was no immediate prospect of any day-care provision for them. There was also the question of what was on offer: the "industrial" activity of the main training centre; or the occupational diversion of the special care or special needs units. These relatively small, more highly staffed areas within the training centre catered for people with severe or profound handicaps, their principal activities comprising training in basic personal and self-help skills, and early cognitive, language, and manipulative abilities. The training materials used are much the same as those used with pre-school or infant children and, although training might be a stated objective, much time is spent using the materials in ways that have long since been learned.

There was a considerable conflict of philosophies here and a problem in deciding what would represent Shirley's best interests. On the one hand, it seemed correct that Shirley (and others in her position) should have the chance to go out during the day and follow some worthwhile occupation. She would gain an increased range of activity, expand her social network, and not be confined to the world of family and the other adults and staff of the house. On the other hand, in the absence of a day-care place she had developed a strongly adult life style involving housework, shopping, and use of community amenities. The opportunity to join a special care/needs group did not seem an attractive or progressive alternative. Even the standard of the main training centre caused concern: the relative lack of intensity of activity; the low level of demand made of the people who were considered to be most handicapped; and the lack of support for individual development. Further, this large, segregated setting had some disadvantages similar to those of the residential service Shirley had only recently left.

Shirley was considered by training centre staff as being in the "grey area" between the more school-oriented special needs unit

and the main "work" area. On first application she was said to require special care. However, by the time a place was finally available, opinion had been swayed by the reports of the progress she had made. She was offered a trial period within the main centre. Reservations were expressed over her history of disruptiveness, her lack of communication, and her deafness. These were realistic concerns because of the extremely low staff:trainee ratio within the workshop and the known difficulties for introducing and integrating new trainees to the particular tasks and general routine of the setting. At the same time, staff at the house had been discussing the possibility of finding Shirley an independent job based on her capability in domestic work. They did not know whether this was realistic, but they knew they had the capacity to support her in a job were they able to get one for her because at that time the house was not fully occupied.

With no great hope of immediate success, staff began to inquire about domestic work available locally. Surprisingly, a part-time job was quickly secured on a three-month trial in a firm which contracted to clean office blocks at the end of the working day. At the same time a place in the adult training centre also became available. As an insurance against the job not working out, Shirley began attending the training centre as well as starting her job, but only part-time so that she would not be absolutely exhausted by moving from a situation with no work to one which involved even longer hours than usual. In the event, the training centre place fell through first: on her first day Shirley had an aggressive outburst which staff felt was beyond their management. The possibility of exclusion was raised. House staff decided to take pre-emptive action. They withdrew Shirley from the training centre voluntarily to avoid an official decision being made against her: still being uncertain whether her employment would be sustained they wanted to retain the possibility of re-securing a training centre place if necessary.

Over the next two months Shirley went to work in the early evening with a member of staff, whose role was to teach her the job routine and, at first, to make good any shortfall in her standard of work by acting as a co-worker, helping to do the job directly. Shirley made substantial progress in learning the required sequence and thoroughness of the job. Direct staff help lessened and the firm supervisor was pleased with the arrangement. However, near the end of the trial period she had one bad day; an

aggressive outburst occurred at work during which Shirley ripped some posters and papers from an office wall. This alarmed other members of the work force and employees of the firm whose offices were being cleaned, as well as causing actual damage. Staff made good the damage as far as was possible and her employer was sympathetic to the incident. However, Shirley lost the job. The house staff were not dismayed. In discussion afterwards, staff thought the job Shirley had been given was particularly exacting. On one occasion when Shirley had been ill, a member of staff had done her job in her place in order to avoid jeopardising the trial. She found it involved continuous hard work to complete the assignment, harder it seemed than was required of others on the contract. They decided not to appeal against the decision but to find Shirley a better job.

Shirley's next job involved cleaning a public house before opening two mornings a week. Again staff support was provided to ensure Shirley's safe travel across town to the job, to teach her the specific requirements and, at first, to give direct help. During the following year, two developments occurred. As Shirley became more proficient, the staff role reduced to that of escort for the journeys to and from work only. Secondly, as other domestic employees left the pub, Shirley was given their jobs also, building up to her working for two hours every week-day morning. She earns the proper adult wage for the job and has been re-employed now through three changes in landlord. At first staff had agreed to cover any absence due to sickness by doing the job themselves, but after about a year, her contract was renegotiated to remove this arrangement. Staff support is now limited. For a while it ceased completely because a volunteer acted as escort, but now Shirley is being taught to make the journey independently and staff input is needed for this. It is likely that staff support will need to be reintroduced from time to time. Periodically, especially with a change in the management of the pub, Shirley's job is redefined; a different order of cleaning, or a change in the areas to be cleaned, is introduced. When this happens, because her deafness and limited use of sign language make communication of change difficult, staff are responsible for helping her adapt to the new requirements. The method of teaching is essentially habit training; while Shirley is in the process of learning the new routine, staff presence is required.

Recently a researcher, interested in looking at people with

mental handicaps in competitive employment nationally, accompanied Shirley to work in order to describe her situation. The following is abstracted from her account:

"I visited on two occasions. On my first visit, Shirley was in bed with 'flu and could not go to work, a very rare occurrence. I did not meet her, but had a chance to talk to the person in charge of the house about her background and the job. On my second visit I was able to accompany Shirley and Rosa, a member of staff, to the pub, where I watched Shirley work, and talked to the landlord, John.

On my second visit, I arrived at the house at about 9.00 am. Shirley was washing up the breakfast dishes. Before we left, she made us a cup of coffee which we drank in the lounge. Although she has no speech, we communicated with smiles and a little Makaton.

Soon she seemed to realise that it was time to go and, without reminder, went upstairs to get her coat, walking stick, and dusting cloths. Shirley, Rosa, and I walked through the town centre to get to the pub. Shirley pushed the button at the road crossings but it was difficult to tell whether she could see the 'green man' or traffic.

When we arrived at the pub, John was busy talking to a delivery man. Shirley went straight in, took off her coat, and got to work. She had been taught the job sequence and how to do each task by staff of the house. This careful teaching had taken about six months plus two months of 'fine tuning', but Shirley now knows the routine and works very independently. Shirley washed all the tables, chairs, and surfaces, vacuumed the carpets, cleaned the toilets, washed the floors, polished the tables, chairs, and bar, and put beer mats and ash trays on the tables. She worked very quickly and with no reminder of the next task. Rosa occasionally pointed out a corner that she'd missed because of her sight. While Shirley worked I took photographs, after asking her permission by showing her the camera and getting her nodded agreement. After I'd taken a few, Shirley came to get me when she started a new task, pointing to the camera and obviously posing.

While she was working I also had the opportunity to interview John who was accompanied by his three-year old son, Thomas. John is not the real landlord, but he and his partner own a small brewery, and this and another pub. John is filling in while waiting for a newly employed landlord to take over. Another landlord initially employed Shirley although John was aware of her employment and has known her since she started work at the pub.

John said that at first Shirley wasn't paid for her work and she had been taken on to get a little free cleaning and also to help her out. (Staff later told me that John may not have realised that she was paid at first.) Later, when she was employed as the cleaner it was definitely on merit. John said she cleans the pub very well: 'The pub gets a good going over. It's much cleaner than the average pub'. John reported that there were still occasionally times when Shirley would get upset and perhaps break her spectacles. Once she broke an ash tray, but these (occurrences) were very rare and not of concern to him. There had been a time in the early days when she'd pulled the hair of the young daughter of the previous landlord but the family was very understanding and neither they nor the little girl had been overly upset by the incident.

John said he felt there were many benefits in employing Shirley. He had seen her develop and gain confidence: 'I can tell when she's enjoying herself, she's a good worker'. He also felt that he and his family had benefited from knowing Shirley and that his four children seemed to have gained insight into other people's handicaps by knowing her. The regular customers know Shirley and many have commented that they think it's very good to have Shirley working there.

When Shirley finished cleaning she put on her coat, gathered up her materials, and came to John for her pay, which she gets each day. She has recently been learning to write her name so that she can sign for her money. Shirley signed her name and John gave her the thumbs up sign and said "good". Shirley smiled brightly, gave him the thumbs up sign and waved good-bye. John said, 'She doesn't like to hang about. She likes to get on with things'.

As we walked back to the house, Rosa said they often stop in town for coffee or to do a bit of shopping but today they needed to get back because, on Thursday, Shirley goes to her father's home for lunch with her sisters. Shirley has recently purchased new curtains for her room with money she's saved from her earnings and is also saving for a holiday.

Watching Shirley clean the pub, get her pay, and walk cheerfully home to meet her sisters for lunch, I couldn't help thinking of her previous life pushing a doll's pram around the hospital grounds day after day. The fact that Shirley has a job is certainly a credit to the staff of the house who persevered against what would seem to most people to be insurmountable odds. It is also in large part due to the pub landlord who was willing to give Shirley a chance to show what

she could do.

But the real achievement has been made by Shirley, who with the opportunity, help, and support, is doing a real job and getting paid for it."

(Taken from Porterfield and Gathercole, 1985.)

Disruptive behaviour: a person from a "locked" ward

Anyone meeting Shirley now would find it difficult to believe that the person busy at work or helping to run the house, herself small in stature, should ever have been considered someone whose problem was defined primarily in terms of behavioural disturbance. Yet she had lived for thirty years in a hospital ward specially designated for such people. When the feasibility of community living is debated it is often people in secure institutional environments who are cited as those who cannot be cared for in ordinary domestic houses. Three people described in this book came to 10 Summerton Road from locked facilities. So what sort of challenge did their behaviour present? In this section we explore this question in relation to Shirley. What was it she actually did? How was it interpreted in the hospital? What was the hospital staff response to it? How was it interpreted differently in Summerton Road? What was the response of the staff there?

Throughout most of Shirley's life, periodic outbursts of severe, aggressive behaviour have been part of the picture. The majority of her hospital notes and any planned treatment she received in hospital was related to her aggression. There were regular entries in her psychiatric notes which recorded continuing disturbed behaviour. She was prescribed major tranquillisers and hypnotics to be administered daily. She was also prescribed more powerful doses of similar drugs, to be used at the discretion of nursing staff, to sedate her after a severe outburst. In her notes were about six "incident forms" per year describing attacks Shirley had made on other people. These forms also described strategies staff had adopted for dealing with the attacks, which included secluding Shirley in a side room and dressing her in restraining clothing. There were also a number of casualty notices which recorded injuries Shirley had either received from the attacks of others or inflicted on herself. The night report book from the ward frequently recorded attacks on other people in the dormitory, which involved Shirley turning them out of bed. Both the pattern

of behaviour and the type of treatment given by staff were evident way back into her childhood and throughout the three-and-a-half decades Shirley spent in the hospital.

There was little evidence of any attempt to understand her aggression other than by a psychiatric explanation; that is, her attacks were crazy, senseless, a symptom of her being deranged. Her medication was the same as that given for acute and chronic schizophrenia and maintenance of psycho-sedation in people with major psychoses. The fact that the frequency and content of her outbursts and the recorded comments about her remained similar over more than thirty years showed the treatment and continual adjustment of medication did not eliminate the pattern of behaviour. Rather than looking to a questioning of the psychiatric assessment, the records seem only to have confirmed the underlying diagnosis. Other possibilities had been hinted at but never followed through to the point of affecting what happened to Shirley. A relatively recent nursing note had suggested a possible association between her outbursts and her menstrual cycle. In the last year of her stay in the hospital, prompted by a change in Shirley's consultant psychiatrist, a referral for a psychological opinion was made. The psychologist was concerned about her lack of occupation and suggested enrolment in the adult education activities and sign language classes within the hospital. An improvement in general spirits at that time and a concomitant reduction in disruptive behaviour were attributed to Shirley having a new doll's pram to push around the hospital grounds. In terms of length of report, this appeared to be the most thorough and coordinated attempt to understand why Shirley might choose to attack others and inflict injury on herself. Unfortunately, no action was taken to increase the range of activities available to her.

After moving to 10 Summerton Road, Shirley's disruptiveness reduced dramatically. A number of inappropriate but mild attacks on others did occur (simple pushes or slaps) which seemed to be a method of communicating her annoyance at their intrusion and a signal to be left alone. Typically, Shirley would be moved from the situation and staff would show disapproval. She always seemed sorry for her actions. Then, after what appeared to have been a "honeymoon" period in the home of about six months, during which Shirley was very happy and showed no sign of major disruption, a number of more severe incidents took place which followed the same kind of periodic occurrence as before.

Outbursts were of the following types: self-injury of the face around the eyes, which usually broke her spectacles, often coupled with an extreme state of excited anxiety which resulted in damage to the physical surroundings (for example, tearing the poster from the office wall at work, throwing a plate, hitting the wall with her fist); pulling the hair of nearby staff or other adults living in the house in an unprovoked attack; and, on about two occasions in as many years, tipping the person sharing her bedroom out of bed. Again, afterwards Shirley showed every sign of being sorry for what she had done.

These outbursts were quite sudden. Staff naturally reacted with surprise and sought to protect other people living in the house and their own well-being. In this they displayed signs of disapproval, while also seeking to calm Shirley, holding her hands down, removing her from the situation, and telling her to stop. These measures were quite sufficient. Since moving to the house, it has never been necessary for Shirley to experience sedation, the use of restraining clothing, or seclusion.

Despite the impression that might have been gained from her recorded history and disruptive status, Shirley's disturbed behaviour has never been so extensive as to constitute a serious problem of day-to-day management. Nor, in contrast to much that is suggested about people with mental handicaps, was it ever viewed as an impediment to her living in the community. Whether Shirley could or should continue to live at 10 Summerton Road was never at issue. However, the attacks, particularly given their re-emergence after a tranquil period, were taken very seriously indeed. It was very important to understand them and prevent them recurring if it was at all possible. Shirley's self-injury could jeopardise her already limited eyesight, and in practical terms it was expensive in repair or replacement of broken spectacles. Her attacks on others, as well as being mildly injurious at the time, interfered with a healthy growth of relationships and trust. Attacks on staff also had the potential of being severely detrimental to working relationships but, in fact, never proved to be.

In order to try to find the basic cause of the outbursts a record of incidents was kept and compared to Shirley's menstrual cycle. At the same time, an attempt was made to analyse whether there were conspicuous environmental precursors or consequences that may generate the behaviour. For the major outbursts none could

be found; and the tie to the menstrual cycle was only partially convincing. Staff did notice that prior to an outburst, Shirley seemed to show signs of discomfort; either rubbing her stomach, or feeling her brow, or both. Shirley's deafness and lack of sign language still enforce on her a substantial degree of isolation and, although she continues to learn signs and use them expressively, acquisition takes time; added to this abstract notions are much more difficult to teach than comparatively simple labelling of objects and actions. One possibility was that her aggression was associated with being in pain, something which she had no means to tell anyone about. It seemed quite reasonable to assume that pain might provide a setting condition for outbursts of irritability that could take the forms described. The consequence of her aggression in the past had been seclusion or restraint. Both imply removal from a possible source of irritation, the absence of demand, and the opportunity to rest. Sedation guarantees this. It is not beyond belief that the treatment she received in hospital reinforced her aggressive behaviour.

This analysis also helped to explain the periodic but variable relationship of outbursts to her menstrual cycle. If Shirley suffered from pre-menstrual tension, there would be a tendency for periodic recurrence of pain. It may not always be so acute that Shirley would be unable to contain her distress and thus the relationship may not be consistently observed. Moreover, other sources of pain (mild illness, headache) could cause distress at times unrelated to the menstrual cycle. Enduring shifts in base-level mood, such as may have been caused by the acquisition of a new pram or the move to 10 Summerton Road, may also have changed the likelihood of an extreme demonstration of irritability.

We were in the position of trying to make a reasonable picture out of a number of seemingly relevant observations. We could have been entirely wrong, but staff thought it was worth following this direction a little further to see what a treatment programme based on this interpretation might be. It appeared to have two dimensions. One was to try to prevent the pain early in its onset. In the final analysis, however, this could only be reliably detected by Shirley herself and she was unable to tell us about it. Therefore a second dimension was to teach Shirley an alternative response to aggression in order to communicate distress and gain relief. The absence of an ability to communicate directly with Shirley, coupled with the low frequency of occurrence of the problem,

meant that staff had to be patient and seek a long-term re-education process. It was decided to try the following. The problem of tipping people out of bed at night could be remedied by Shirley having her own bedroom. Carol, who had initially been given a single room, had developed some interests in common with Kathleen, who had only recently moved to the house. They began to share a room and Shirley moved to the vacated single room, a move which pleased her. Secondly, Shirley was given a course of prophylactic medication in the middle of her menstrual cycle designed to regulate and ease any pre-menstrual tension. Thirdly, a programme of teaching Shirley to look after and take mild analgesics herself when needed was started. In addition she was given regular opportunities to rest, without having to resort to prior aggression. Lastly the signing of discomfort by rubbing her stomach or temple was encouraged and the *Makaton* sign for "pill" was taught.

Disruptions are now much reduced in frequency and severity. Staff still have some difficulty in deciding when Shirley is sufficiently off-colour not to go to work or when they should encourage her to be less active in the house. So much of her activity is self-initiated these days that it is a matter of encouraging her to put her feet up. If she lived with less people, or with people who were not handicapped, the few outbursts which do still occur may not happen. There has been one incident at the pub, which may have been due to her working while ill, but her current employers appear to accept that this may occasionally happen. Staff in the house also accept there may be the odd incident. Basically such events are shrugged off. Shirley is no longer defined by a behavioural manifestation which occurs infrequently, lasts only a short time, and ends without the need for intervention.

Three years on

Three years after moving from the hospital where she had lived since the age of six, Shirley is living in a comfortable, well-furnished house in a pleasant town, with a regular part-time job and close involvement with her family. Given the philosophies to which staff of the house adhere — the importance of participation, development, and the treating of people who have reached the age of majority as adults irrespective of their level of handicap — Shirley is able to make choices which concern her welfare, initiate activity on her own and on others' behalf, and take on adult

responsibilities. Her life has an adult routine which she has adopted without the benefit of language. She appears to know the time of day and the days of the week. She gets up and prepares for work Monday to Friday, but takes a more leisurely view of things at week-ends. She anticipates mealtimes, changes in staff shifts, and her relatives' regular contact. Like other people who work, Shirley takes holidays; some of which she spends at home and others on vacation (with staff and one of the other women). Again, like other people who work and who have household responsibilities, she has a meaningful sense of leisure; gardening, watering the indoor plants, and watching television are hobbies rather than "occupation" or "therapy".

Despite all of this it is still clear that there are limitations to her freedom and development which are inherent in living with a group of other adults with severe or profound mental handicaps. These are brought about partly by living in a social world defined by skill deficiency and partly through the simple need to conform to the order of a group routine.

Gaining a job provided an important complementary emphasis to the development of a different way of life for Shirley, which followed moving out of hospital. In this respect, Shirley has achieved more than the other people living in the house (and more than most people with mental handicaps who attend adult training centres). She has achieved the status of an employee, paid at parity with other citizens who have no disabilities who undertake similar employment. But not only that, she is doing something which is entirely individual to her. Part of her life is arranged with just her in mind and for her own benefit. There are demands which she has to meet independently of the people who share the house with her and under her own steam. In contrast, the adults who go to the day-care service from the house do so as a group. They used to go in organised transport, all at the same time, although Carol now makes her way independently on public transport. But the similarity and sharing of demands means that those going to the day service provide cues for each other and the staff routine is determined by their needs as a group. There is a collective responsibility and in this each individual escapes a certain amount of personal responsibility.

Gainful employment has also meant that Shirley has an income of her own which has obvious benefits. One is that she can begin to afford some of the things which help adults meet their

commitments and responsibilities. Monday to Friday she needs to get up in time to go to work. She has an alarm clock to wake her; one which she can place under her pillow and which signals by vibration. She has an automatic tea-maker in her room to help her start the day. Out of her own pocket, Shirley has also been able to refurnish her room, redecorate, and replace the curtains and some linen.

Having an income also led to a consideration of how to teach Shirley to use a bank. Given her language difficulties and her late start in learning any form of communication, we decided that it was unrealistic to expect her to learn to read or write. The writing of cheques was not considered a possibility. However, we are now in the age of the computer and the cash card economy; more gets done simply by pushing buttons. Shirley had some understanding of number. For example, she would usually lay the correct number of places at the lunch table even though the number of people taking lunch would vary from day to day. To enhance this ability, a formal programme of matching quantities to numerals was undertaken. Her success indicated an obvious ability to discriminate numerals: this was taken as a starting point for teaching her to use the bank's cash dispensing machine. The target set was to teach Shirley how to push the sequence of buttons to enter her personal code in the machine. As such machines have a safety device of confiscating the user's card if consecutive errors are made in the keying in of a personal number, the teaching was conducted initially on a desk-top calculator which had a key configuration similar to that of the cash dispenser. This had the added advantage of giving visual feedback on the correctness of keying to the model. Once Shirley succeeded in this she progressed to using the proper machine and was given further instruction on the other steps involved. An earlier programme had already taught her to sign her name. Shirley can now sign for her wages, sign her paying-in-slip when banking them, and get her money out of the bank when she needs it.

Shirley's inability to communicate is still a major difficulty. Her knowledge of signing is increasing. She currently uses most of the signs in the first two levels of the *Makaton Vocabulary* (Walker, 1980) which are relevant to her life, as well as other interpretable gestures. She has both expressive and receptive abilities in this respect, but the joys of conversation are still not available to her. Shirley's clothing and grooming is better than when in hospital;

she dresses smartly, appropriate to her age. She is presentable and stylish. This is attributable partly to income, partly to a wider range of choice that the shops in the local town and neighbouring cities offer, and partly to her clothes being better laundered and, if necessary, dry cleaned. At root it also reflects a staff and service orientation that these things are important and cannot be neglected with an easy conscience. Blame cannot be transferred to the handicap of the person suffering the neglect.

Considerable change has been accomplished. Already Shirley has developed so much in a few years that the question of a move towards further independence must be considered; a placement which will provide her with greater opportunity but still within a supportive structure. The change we have seen has often belied the formerly consistent assessment of Shirley as a person in the lower range of the category "severely mentally handicapped". Perhaps because her deafness made accurate assessment difficult it is possible that her intellectual impairment may not be as great as test results suggested. In a developmental assessment we conducted as part of our research at the time of her move, Shirley had no measurable ability in hearing and speech. She passed items concerned with eye/hand coordination and manipulative performance to the level of normal three-year-old development, and some of her locomotor and personal skills were typical of six-year-olds. As a woman in her forties, there was no question that she was severely delayed. Moreover, in terms of her life style, the experiences that she has had, and the progress she has made, a reappraisal of the precise severity of mental handicap after the event is somewhat academic.

It is important to realise that not everyone considered severely mentally handicapped moving from a large hospital will develop as dramatically as Shirley; but the fact remains that some may. Shirley is unlikely to be the sole example. It is only since moving to the greater opportunities of the small house with the developmental orientation of its staff, that any doubt over the severity of Shirley's handicap has arisen. For thirty-five years professionals were happy in their assessment. However long she had stayed in hospital, would anything have happened to cause any doubt? Could the organisation have been changed to give the same kind of supported opportunity and careful planning? Would Shirley ever even have acquired a pair of spectacles? It is hard to imagine the first two questions being answered in the affirmative.

And even if some "radical improvement" to the institutional organisation had secured the provision of spectacles, would it have managed to replace them every time they were broken by Shirley, by accident, or by another resident?

The other defining characteristic of Shirley's previous situation was her status as a disruptive person. The objective description of her even shortly before her move hardly conveys the picture of challenge which people imagine when discussing whether there are people in the long-stay institutions for whom community care is not a realistic possibility. But someone must have considered her to have presented a serious problem for her to have been resident not just in hospital but in a locked ward within that hospital for so long. We cannot have it both ways. We cannot maintain that the institutional system is necessary and that people who live under more secure arrangements do so because of genuine difficulties of management, and at the same time suggest that people who flourish after leaving such an environment were not really difficult anyway. Either there are fewer people living in the existing institutions who are likely to present severe challenges elsewhere than is often stated; or the stated number of people do exist but their behaviour can change dramatically given new and improved surroundings. Both these alternatives give ground for optimism, providing the orientation and care of the staff at 10 Summerton Road can be replicated in other similar settings.

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