CHAPTER 7

Linda Chandler — some successes, some failures

In telling the story of 10 Summerton Road and of the nine people who have lived there we have, with one exception, sequenced the accounts in the order in which the people came to live in the house. We have now come to our last account, that of Linda, the exception to the chronological order. We have chosen to tell her story last partly to finish with a full chapter devoted to a single account, but partly to emphasise one issue in Linda's story; namely, that her admission to 10 Summerton Road was not clear cut. It is difficult to state a precise date as to when it occurred. There was an extended period of indecision in her initial experience of the service during which she lived mostly at home but also sufficiently in 10 Summerton Road for her to be viewed officially as someone living there permanently. Linda became involved with the service on opening but did not come to spend most of her week there until fifteen months later, after Richard and just before Margaret had moved in. A more decisive course might have been to Linda's benefit. Indeed a feeling of dissatisfaction with our efforts on behalf of Linda runs throughout her story. There has been some achievement, but it has been reached with considerable difficulty. Progress has been slower and decision-making more problematic than for some of the other people we have discussed.

First involvement

Linda lived locally and attended the special care unit of the local authority adult training centre. She lived with her parents and elder sister. Her sister was a member of the parent group which met the people planning the 10 Summerton Road service monthly prior to its opening. We have already referred to the differences of opinion that arose concerning the admission policy for the house. Members of the parent group were keen to have a panel judging the priority of individual need upon which they would have representation. We argued for a service on demand, and held to the view that it was not possible to weigh one person's need against another's. In the short-term, while service supply was still

deficient, some people would necessarily have to wait. The nub of the argument lay in the fact that, as we have described, Catherine's family were in desperate need and the local parents' group was looking for an arrangement which would guarantee Catherine an immediate service. We also had the impression that they considered a residential place for Linda as another immediate priority.

Linda was eligible for admission to the house within the policy stated by the authority. The availability of a place was made clear to her parents and sister in the round of domiciliary visits which were conducted in preparation for its opening. Linda's parents, however, were not pressing for her to leave home immediately. They could see that she would require a residential service in the future and appreciated that one would be available but they were content for her to continue to live at home for the time being.

Linda's family had developed better cooperation from Linda than staff could manage, either in her day-care setting or later in the house. At various times they have registered surprise when it has been reported to them that Linda has been presenting problems to the services dealing with her. Linda behaved differently at home; her difficult behaviours were least in evidence there.

Over many years, both as a child and as an adult, Linda has posed major problems of management to the education, social services, and health services that she has attended. She has been frustrating to work with because she has given a hint of hidden abilities which she would not subsequently display, masking them by a dominant overlay of repetitive, bizarre, self-stimulatory behaviours and a stubborn, non-compliant attitude which paid no regard to the efforts of staff on her behalf.

Linda has Down's syndrome, is short in stature (less than five feet tall) and, when first in contact with us, was very overweight. Her face, around her mouth and eyes, was sore and inflamed. She had straight hair, simply cut. Her mother said she liked to keep her looking young. She put considerable effort into the clothing she bought and adapted for her. She would buy dresses which were sufficiently broad for Linda to get into and then alter their length so that the hem came just above her knee. When sitting or walking her dresses tended to ride up, revealing her thighs and the top of her tights. She often needed to pull her dress off her bottom entirely when sitting in order to be comfortable.

The main problem was one of cooperation. Although affectionate to staff, Linda tended not to follow their requests. She would reinforce her decision not to join in by deliberately being destructive, deliberately wetting herself, or by being aggressive (pinching, punching, and pulling hair). Staff could have been forgiven for thinking she was baiting them; for example, by pouring a half-full cup of coffee down the front of her dress while they were watching. In the time she thereby created to be left by herself, Linda engaged in a variety of self-stimulatory arm movements, finger movements, head movements, facial grimacing, and vocalisations, sometimes singly but most often in complex combinations.

Beginning to shape the residential care programme

Discussion with Linda's family resulted in Linda embarking on a gradual transition from living at home to living in the house. At the beginning of 1982, Linda began to stay at 10 Summerton Road at week-ends with a view to moving in permanently over the next three months. But the three month period extended to fifteen months. During that time, Linda's sister had three long working trips to the United States. While she was away, the decision to change from Linda staying only at week-ends to living more permanently at 10 Summerton Road could not be reached. Linda's parents said that such a change must wait for her return. Service involvement in relation to Linda, and Linda's own state of residence, was therefore held in limbo for the rest of the year. Linda was a week-end guest but she lived mostly in her family home; her greatest service involvement being still with the special care unit. As a consequence the first fifteen months was a time during which certain directions for movement were identified but little was achieved. Overall, our impression of "phased-care", which we experienced with both Linda and Kath, is that it was of little benefit to either person. It generated confusion rather than adjustment.

Other than the programme planning issues surrounding Linda's admission to long-term care itself, objectives set at this time concerned her appearance and her repertoire of problem behaviours. Linda's strong tendency towards not following instructions competed with the likelihood of her becoming involved in meaningful occupation, interfered with her ability to learn, and caused her to be denied opportunities for participation

in community settings. Teaching objectives concentrated on self-help and household skills; establishing full continence was another early concern.

Improvement of Linda's appearance included three elements: weight reduction, through diet such as was in progress with Catherine; treatment of the discolouration of her skin arising from the soreness around her mouth and eyes; and, the encouragement of a more adult wardrobe, footwear, and hairstyle. The first two of these objectives were clearly relevant to her immediate and longer term comfort and health. Added to these, Linda's self-stimulatory rituals and mannerisms had a profound effect on her appearance. Even if her size were to be reduced drastically and her style of dress brought into line with that associated with a woman in her middle-to-late thirties, Linda would remain conspicuously peculiar by virtue of her chosen activity.

Reviewing these objectives with the benefit of hindsight, it becomes clear how unhelpful the extended period of "phased-care" was to beginning the process of change, let alone to gaining its successful achievement. While Linda continued to live mainly with her parents it was natural that the bulk of her wardrobe should be kept at their house. Her weight was largely determined by the diet she followed at home and at mid-day at the day service. Moreover, there was constant interruption to the development of a strategy by which gradually to increase her cooperation and involvement in household life. It was difficult to develop a consistent approach to dealing with Linda's non-compliance, let alone her array of stereotypic behaviour. Through the first two review meetings, objectives were largely recorded as unattained, still in progress, or not even programmed. Apart from supporting a general introduction to the full range of household activities available to her in the course of her regular stays, the residential service could not generate behavioural development in two days a week. The residential staff made a contribution to the discussion and content of the individual programme planning but this in itself had little effect, other than in setting a foundation for the future.

Spending more time at the house: the service begins to respond to Linda's difficult behaviour

Throughout 1982, Linda's needs as we perceived them remained largely unmet. This was during the period in which substantial progress was being achieved for Shirley, Catherine,

and Mary. By comparison, there was a feeling among those concerned with the house that the service had failed Linda. We could not help thinking that we might be avoiding the difficult issues that had to be faced in developing a service intervention that would be in her best interests.

In January 1983, Linda changed from living at 10 Summerton Road at weekends to living there during the week but going to visit her family at weekends. This meant that she spent four nights per week in the house but because she also attended a day service Monday to Friday she was still there very much on a part-time basis. When in the house she had a disrupting influence and staff were keen to become more effective in helping Linda settle and enjoy life more. Their concern for the continuing damage that Linda's behaviour was causing to the management of the household, to the way other people viewed her, to the growth of genuine affection towards her, and to her own progress and development was shared by the staff of the special needs unit of the training centre. They had, after all, been looking after Linda longer and as well as seeing her disturbed, non-compliant behaviour as an obstacle to her own development were feeling personally worn down by the task of competing against it and putting up with it. No-one had an immediate strategy as to what to do about the problems Linda presented.

At this point, it may be helpful to give both a definition of the term "self-stimulatory behaviour" and a fuller description of how Linda behaved. "Self-stimulatory behaviour" is a term given to a group of different body, limb, or finger movements and to the making of noises which appear to the outside observer to serve no meaningful or comprehensible adaptive purpose. These events are also called "stereotyped" behaviours: each person's self-stimulatory behaviours being repetitively the same and following ritualistic patterns. Common and obvious examples of such behaviours are body-rocking (repetitive bending at the waist to cause deflection from and return to a vertical position, either when sitting or standing), pacing (back and forth or in a circle), and repetitive hand movements in front of the eyes. Other forms include repetition of noises, repeating words (echolalia), and visual fixation to a light source or some form of motion (often circular). The term "self-stimulation" is based on an inference that, in the absence of an identifiable external consequence to the behaviour, the person must derive pleasurable internal

stimulation through activation of the central nervous system.

Linda performed many of these behaviours including body rocking, arm movements, flicking of her fingers, making the noise "amp" repetitively, shaking her head, pulling faces, and violently throwing her head back. Whereas most people have funny little mannerisms that become insignificant and even unnoticed in their constant stream of varied, constructive activity, a few develop such behaviours as their dominant form of occupation, to the exclusion of virtually everything else. The behaviours then constitute a serious problem, appearing to block alternative sources of sensory input. They become highly treasured forms of activity that may be defended by temper tantrums, destructiveness, aggression to others, or self-injury. They interfere with social processes, with the development of meaningful relationships, and with learning from others. They also affect other people, particularly if they do not understand the nature of the problem. Self-stimulatory behaviours can be intrusive and wearing; people can get annoyed and frustrated if the person displaying them cannot be stopped from behaving in such a way. In a group situation the person in question may have no interest in the group activity; the disruption caused may detract staff attention and disturb the attention and enjoyment of others. All these factors are likely to result in the person becoming vulnerable to being excluded from many situations which contain opportunities for meaningful occupation. Even though the person may voluntarily avoid making good use of such opportunities, loss of opportunity may still be considered an important negative consequence. It is important, when staff develop competency to care effectively for such a person, that the person should still be allowed to remain in a situation where there are opportunities that can be exploited to the person's advantage.

Although Linda had begun to live at 10 Summerton Road more than previously, she still went home regularly at weekends. She also spent a number of complete weeks with her family during holiday times. At the March 1983 individual programme planning meeting, the subject of her inappropriate behaviour was again raised by staff from both the house and the special needs unit. It was agreed that some attempt to analyse her behaviour should be made. An American expert in behaviour modification was working with us at that time and he was asked to make an assessment in liaison with the staff of the services concerned and

the community psychologist. Linda's behaviour was carefully observed: during lunch-time breaks at the adult training centre; in the special needs unit both while Linda was involved in activity and while she was left alone; and, later in the day, on returning to the house. The observations looked for any pattern in the onset, duration, and cessation of repetitive noises or movements which could be linked to environmental events: specifically, whether staff were contacting Linda, whether staff were leaving her alone, whether demands were being made of her, whether she was free to choose her activity, whether she was alone or with other people, and whether staff were giving attention to other people.

The assessment yielded a number of conclusions. First, Linda engaged in some form of self-stimulatory movement or vocalisation virtually all of the time. There were differences in intensity or modulation which appeared to be related to the attention and demands she was given, but there were seldom times when she was not engaging in some form of stereotypic behaviour. Second, this observation held true over a number of environmental conditions and staff behaviours. This suggested that her behaviour was not closely linked to what was going on around her. Third, while the amplitude of Linda's stereotypic behaviours (including visible signs of emotional upset and associated non-compliance) may serve to deflect staff demands to become involved in alternative activity, staff in the special needs unit and at the house met with some success in asking Linda to do things. Certain approaches were more successful than others. Nonetheless, such behaviours continued as a constant backdrop to other activity.

Although, following assessment, no specific recommendations were made to reduce Linda's self-stimulatory behaviours the following procedure for staff interaction was recommended as a means of gaining her cooperation:

1. *Give clear, short instructions to Linda in a calm tone of voice, soft to medium volume.* (This was noticed to be particularly effective when the staff member's face was very close to Linda's while the instruction was being given. If necessary the staff member was to touch her on the side of the face to gain her attention.)

2. *If Linda does not follow the instruction, repeat it in the same words, tone, and volume of choice.* (If the initial

instruction had been given from some distance across the room, the member of staff was to move closer and repeat the instruction face to face with Linda.)

3. *If Linda still does not follow the instruction repeat it, this time with a physical prompt.* (Examples of the kind of physical prompt required are: if Linda is to pick up a dropped tissue, the staff member should take her hand and move it about twelve inches in a downward direction and then let go; or, if she has to pick up a jug from the table the staff member should push her hand some three inches towards it.)
4. *If Linda does not respond by this stage, physically guide her entirely through what is needed.* (From our observations Linda is unlikely not to have responded to the procedure followed in 3.)
5. *After she has finished, thank her.* (Linda had showed distress on some occasions when immediately asked to do exactly the same thing again. Staff were to avoid directly repetitious activities and to try to think of how to structure activities so that Linda would have a chance to do several different things before being asked to repeat the first response again. Alternatively, they could consider allowing some time to elapse before asking her to repeat the required action again.)

In relation to Linda's repertoire of self-stimulation, our American colleague was not optimistic that a modification strategy based only on positive reinforcement would prove effective. He saw little hope of successful suppression through the systematic deployment of attention to other behaviours or other positive educative means. He thought we would have to consider direct, active, and consistent discouragement of her behaviour.

We could appreciate the truth behind this advice without necessarily welcoming it. There is a general ethos in favour of employing positive means to change behaviour, ones that are educative in nature and are used generally and widely within a person's social culture. There are ethical concerns when aversive means of control are employed, which must be properly addressed. The intention is to find an acceptable means to reach a desirable end. In so doing it is important not to shirk the

responsibility to help someone in need of treatment, even if the means are difficult. The end result may be important enough to merit the approach chosen but it is easy to predict that the mere discussion of the possible use of punitive strategies will almost certainly occasion hostile reactions from others. People may not always share the same aspirations for people with mental handicaps in general, or for a particular individual. They may not agree on the definition of benefit or on the suggested course of action to be taken.

Introducing aversive measures is not an easy matter. It is, in fact, far easier to leave the pool unrippled; to live with the *status quo*, knowing that there will be no tangible consequence for failing to address the issue, other than the pricking of one's conscience in knowingly avoiding action on a dependent person's behalf. Neither the house staff nor the day-care staff would be unusual in declaring themselves unable to bring about a dramatic change in Linda's behaviour. Nobody else was stating the need for it to be changed. Nobody else was looking for improvement in the quality of Linda's life, her abilities, her experience of life, or what she got out of it. Her parents seemed content with circumstances as they were and Linda had no other advocate, outside of the services, acting on her behalf. Linda herself, although seemingly deriving little pleasure from her daily round, had never stated any desire for change. (She appears to have greater language ability than she uses, it being masked by her self-stimulatory behaviours. It is difficult to assess her ability accurately but, in her most lucid moments, it is possible to have a meaningful conversation with her based on the exchange of phrases. On the *Derbyshire Language Scheme* (Knowles and Masidlover, 1982) rapid assessment, Linda can hold and respond to three information carrying words: verb, preposition, object. However, there is a danger of overgeneralising the impression of her ability. The fact that she can sometimes converse in short sentences does not mean that she always could if she so chose.)

If programmes of management involving punishment are to be entered into, they must be established in a proper manner, following full consultation and with a proper consideration of the importance for the individual of the target behaviour change. An estimate must be made of what would result from successful programme implementation, and how this would compare to the person's future circumstances if the problem behaviours were to

continue unaffected. It is desirable to examine alternative positive strategies directly, rather than relying on expert opinion that they might prove fruitless. It is important to consider whether full suppression of the undesirable behaviour is desirable or practical. For example, in relation to self-stimulation, it might be decided to retain certain times and places where the person can choose to continue to behave in such a way, for example, while having a break from household chores in the living room. Before embarking on any routine strategy of management throughout the day, it is necessary to make sure that the procedure to be adopted is effective and that staff are willing and competent to implement it.

A further difficulty in interpretation and decision-making as far as Linda was concerned, was the report of her behaviour at home. The extent of her inappropriate behaviour was viewed as being much lower by her family than by service staff. In interviewing Mrs. Chandler for research purposes, she reported that Linda did not threaten or inflict injury on other people, and that she did not damage property or have temper tantrums. She also said that Linda did not disrupt others' activities or display a lack of consideration of others, except for occasionally disturbing people watching television in order to gain their attention. The only stereotyped mannerisms she reported were body rocking and rubbing hands together. She made no mention of any peculiar noises or repetitive vocalisations. She did say that Linda was occasionally upset when thwarted or criticised, and that she was overly particular about where and how to sit; liking to sit with both legs crossed on the chair. In a similar interview with residential care staff, Linda was reported to show a more extensive variety of self-stimulatory behaviours and more serious problems of aggression to people and property.

The difference between accounts of Linda's behaviour in the family and at 10 Summerton Road did not seem to be one of different perceptions of the same behaviour. It was clear that Linda behaved differently; even if the difference was less extreme than the impression given by the two conflicting reports. Why? She may have been happier at home. Other factors may also have been relevant. Few demands were made of her at home and her chosen pursuits seemed to be accepted more. Requests for her to change what she was doing were likely to be fewer. We had seen, in our observations of Linda, that in a situation which presented

few demands or responsibilities and providing she was allowed to sit as she pleased, Linda's self-stimulatory behaviours were considerably muted. We had also seen the amplitude and intensity of her self-stimulatory behaviours increase to overcome demands made of her, escalating to shouting accompanied by visible signs of distress. An absence of demands might explain why her family did not report examples of aggressive behaviour towards them or the deliberate spoiling of household property. The home environment was tolerant and accepting, and Linda was secure in the love of her family.

While we were still pondering the interpretation and implications of the analysis of Linda's behaviour, circumstances changed within 10 Summerton Road which became of more immediate concern. Linda had always received considerable staff attention, second only in extent to Catherine. Despite staff efforts to help her settle and to be an integral part of household life, Linda began to react by displaying a range of "house-wrecking" behaviours. In damaging the environment she affected others living in the house and hurt the feelings of some staff, causing them anguish. Staff had to attend to the consequences of her behaviour, thus reducing further the amount of time they had available to spend positively with her and the other members of the household.

Linda's disruptive behaviours fell into four categories. Although not all of them were strictly new, there was a marked increase in the severity and frequency of their occurrence. One category concerned damaging the house or making an unjustifiable mess: breaking crockery, tipping over drinks or plates of food, knocking objects such as plant pots or ornaments off shelves or off the mantlepiece, urinating on the floor or furniture, and putting clothing down the toilet. A second category included less damaging disruption of the same sort, involving deliberate untidying of the house. The third category comprised deliberate heavy-handedness in putting objects down: banging them down on table or work surface (sometimes but not always causing cups or plates to break). The fourth category was made up of a variety of other forms of disturbance: hitting others, pulling at other people's clothing, and pulling her own clothing.

An overcorrection approach was adopted to discourage these behaviours. This involved both restitution of the environment and massed positive practice of specific alternative behaviours. "Overcorrection" is a term applied to a punishment procedure

which avoids inflicting physical hurt or giving severe reprimands. It involves making a prolonged period of correct activity the consequence of the inappropriate act, either to remove the consequences of the inappropriate act by making good and improving the environment (restitution) or to do the correct form of the inappropriate act many times (massed positive practice). In either form, the activity is sufficient to make the person prefer to avoid it in the future.

Our analysis of the causes of Linda's changed behaviour was rudimentary; it generated little more than an assumption that Linda was displaying opposition to staff and the structure of household life generally. The overcorrection procedure was designed to demonstrate to her that behaving in such a manner would not be tolerated. Linda was still living a divided life at this time, partly in the house and partly in the family home. Staying in the family home remained a frequent occurrence but the visits had lost all pattern. She sometimes went home at weekends. At other times she went during the week and stayed in the house at weekends. On yet other occasions, she went home for a complete week, including the weekend before and the one after. The person-in-charge of the house and the community psychologist visited Linda's family to discuss the problems being presented and the proposed strategy to deal with them. They also discussed whether it would be in Linda's best interests to make her visits home more regular and not quite so frequent, such as every other weekend. Linda's family were surprised that Linda was causing such problems but gave their support to the management strategy proposed, including regular but less frequent visiting. They were surprised because it had always seemed to them that Linda was happy living at 10 Summerton Road. She had always seemed happy to return there after staying at their house.

The precise management strategies adopted varied according to the nature of the disturbance. They all had the character of causing Linda to practise an alternative, pro-social behaviour and of ensuring that she restored the environment to a state at least as good, if not better, than before. Staff acted in a neutral, controlled, and dispassionate manner. Compared with the somewhat inconsistent negative and emotional reactions which are usual when individuals have difficulty living together, the controlled and premeditated nature of procedures of this kind appears artificial. However, the consistency and absence of

emotional associations have a function. The intention is to communicate to the individual that other people do not like the particular behaviour, not that they do not like the individual. Therefore, when the overcorrection has been completed, and at all other times, the person is treated positively and warmly. Staff have to avoid carrying over a negative attitude from the period of disruption to other times. The fact that they have made a controlled response to each specific presenting problem should enable them to leave every incident behind them after dealing with it.

Overcorrection procedures tend to be time-consuming. Those used with Linda were no exception. Specifically, for damaging objects or making a mess, Linda had to sweep up all visible mess, throw away debris, wash or vacuum the area affected, wash or vacuum the rest of the floor, and replace all furniture moved during the process of clearing up. In all, this would occupy a minimum of ten minutes. For untidying, throwing, and banging down objects, Linda had to replace all items moved out of place, and pick up items dropped or banged, first holding them out for fifteen seconds and then putting them down, in their place or on a surface, gently. She would then have to pick them up, hold them, and put them down again gently a total of twenty times. For pulling staff's clothing or her own, or for hitting other people, Linda had to engage in an arm exercise for five minutes. This involved first holding her arms out at her side for fifteen seconds, then holding them above her head for fifteen seconds, and then holding them straight out in front of her for fifteen seconds, repeating the cycle to fill the time.

Practicalities in following the programme had to be considered. Matters such as what to do if the disruption occurred when Linda was having a bath or a meal, how to ensure other members of the household were as unaffected as possible, and how to prevent Linda from avoiding the overcorrection effort by escalating the scale of her disruption had to be determined. At the beginning, there was a rota specifically designating one member of on-duty staff as the overcorrection trainer. This rota initially comprised the community psychologist and members of the research team connected with the house. The programme of management was conducted throughout September, October, and November, 1983. After the first three weeks, when the frequency of disruptions had declined, management was taken over by the staff

of the house. Records of disruption and implementation of the procedure were kept throughout. These records showed that the "messy" disruptions fell from an average of six per day in the first nine days of the programme to one per day over the next nine days, still averaging one per day in the first nine days of November. "Noisy" disruptions averaged sixteen per day during the first nine days, five per day during the second nine days, and two per day during the first nine days of November. "Pulling" disruptions averaged thirty-six, twelve, and two per day for similar periods. This last category included Linda pulling other people's clothing or hair as well as pulling her own clothing, in particular pulling up her dress at the back as she walked. This behaviour was resistant to change, probably being part of her already-mentioned set of self-stimulatory behaviours. It was not considered an important target to change at this stage. More importantly, the disruption of household life and attacks on staff had virtually disappeared.

We were not altogether satisfied with this episode, or the content and the operation of the programme. There was a feeling that it had been rushed into without adequate prior analysis because of the seriousness of the presenting problems. It served the function of retrieving the *status quo* and cutting short the development of a repertoire of extremely disruptive acts. As a side effect, it had also caused a beneficial change in Linda's living conditions. Linda now had a regular pattern of living primarily in 10 Summerton Road and going for routine stays with her family. The house staff (who have shown great commitment to attaining what they judged to be in the best interests of the people living at the house) did not take easily to implementing the overcorrection. Moreover, the programming issues which had been of concern before — how to gain Linda's cooperation generally and in a more ordinary way, and what to do, if anything, about her self-stimulatory behaviours — still needed to be dealt with.

A more positive approach

The small house service had withstood a period of increased difficulty. The staff at 10 Summerton Road and the staff in the special needs unit had maintained the basic order of their services and their role in other people's lives while also coping with the extra difficulties Linda presented. They now looked forward to improving their mode of interaction with Linda to make

cooperation and purposeful occupation more likely to occur.

During the course of our research, video recordings had been taken of all the people living in the house as they went about their household business. These revealed substantial differences in the way individual members of staff interacted with Linda in the course of the same day. Some staff tried to gain her cooperation almost entirely by asking her to do something. When she responded by ignoring their request, saying "No", or escalating her self-stimulatory noises and movements, they simply repeated their request. There were examples of staff asking something of Linda upwards of ten times in a row to no avail. In the course of this, Linda would refuse by shouting, throwing her head back violently, stamping, banging surfaces with her hand, or displaying other similar forms of disruption. In contrast, other staff asked Linda to do something just once and offered her physical guidance immediately if she did not respond. She usually followed the request with the help given. Whereas the first interactional pattern is likely to teach Linda how to avoid an activity, the second may teach her the desirability of joining in. Even when Linda reached a high pitch of refusal, if staff gave her some physical guidance, there was a good chance of her calming down and joining in.

On the basis of these observations, the community psychologist devised a new programme for Linda, to be implemented first in the special needs unit and then in the house. The primary aim was to increase Linda's participation and promote staff interaction with her when she was usefully engaged in activity. In both settings the programme involved staff observing each other at work with Linda, filling in a specially devised recording form, and sharing with each other their own interpretation of the extent to which the balance of their interactions with Linda showed praise after she had cooperated with their verbal requests. The procedure for staff working with Linda was set out as follows:

1. *Clarify the tasks to be done as a set of discrete steps. Be prepared to give Linda a verbal prompt on each step.*
2. *Before you say anything to Linda check she is quiet and not making "amping" noises, crying, or being otherwise disruptive. Wait if she is not quiet, looking away from her until she becomes quiet. Do this at each step.*
3. *Say to Linda what you are going to do.*

4. *Give Linda the instruction (verbal prompt) for the first step. Allow her about five seconds to comply (follow the request).*
5. *If Linda does not follow the instruction (stays unresponsive, tries to leave, make noises, says "no") give her just enough physical guidance (physical prompt) to do the step you have asked. You may accompany this help with a repeat instruction if you wish but DO NOT REPEAT THE INSTRUCTION WITHOUT GIVING PHYSICAL ASSISTANCE.*
6. *When Linda follows the instruction with physical guidance, praise her warmly and go on to the next step.*
7. *If Linda carries out the step WITHOUT you giving her a prompt or instruction, praise her very warmly.*
8. *AT NO TIME comment on any noises, attempts to leave, or other disruptive behaviour. DO NOT make any disapproving statement. If Linda becomes noisy wait, without looking at her, until she is quiet, then return to giving her an instruction (or physical guidance if you have already given her the instruction). DO NOT allow Linda to avoid completing the task, but BE VERY POSITIVE IN YOUR PRAISE WHEN SHE GIVES HER COOPERATION, EVEN IF YOU ARE GIVING EXTENSIVE PHYSICAL ASSISTANCE.*

The staff observing were trained to record if Linda was quiet, the number of verbal prompts, whether Linda cooperated after the first prompt, the number of physical prompts, whether staff praised Linda for doing the task, and whether staff made any disapproving statements aimed at stopping Linda from doing something. These data were collected in successive columns, each relating to a discrete component of the task to be done. The data were analysed in terms of the proportion of total tasks (columns) for which (a) Linda was quiet, (b) only one verbal prompt was given, (c) Linda complied, (d) guidance was given because Linda did not comply, (e) praise was given, and, (f) disapproval was given. Staff performance was compared against the standards set for successful implementation of the procedure; 90%, 85%, 90%, 100%, 90% and 0% respectively. The observer was also invited to

record any general comments on the session.

The introduction of the component of staff observing each other helped all members of staff to see for themselves some features of their habitual interactions with Linda which differed from what they had thought they were doing. They saw that Linda received praise less often than they had thought and that their primary mode of trying to get her to do something was by verbal request. When that had not been successful, they had simply repeated the request. Rather than seeing Linda as defiant (that is, a person to be viewed unsympathetically), a perception was given of Linda as a woman with a severe mental handicap, with many distracting behaviours and doubtful language capability, who was not getting the direct physical assistance she needed to behave appropriately. This had a generally beneficial effect in changing working practices. Linda's cooperation has increased substantially from this time.

On reflection, our dissatisfaction and self-criticism concerning the relative failure of the home service to cater for Linda's needs and produce some form of positive benefit might be summarised as our having taken a long time to get to first base, something over two years. The outburst of "house-wrecking" behaviour followed a particularly unsettled time, when Linda had spent a week in the house, gone home for the weekend and the following week, come back to the house for the next weekend, gone home during the weekdays of the next week and then from Wednesday to Wednesday after that, been back in the house for seven days and home for five, and back in the house for three days and home for seven. The house staff had been following the policy of promoting free and unconstrained contact with relatives and simply responding to parental requests for Linda to stay with them. The response *to do something* about the problems Linda was presenting to household management reflected the needs of staff more than the careful consideration of Linda's welfare. It should perhaps be regarded as symptom control, where the person with the mental handicap is, wrongly, the exclusive focus of change. Coincidentally, more significant changes were made.

A firm pattern was established as to where Linda lived: 10 Summerton Road became her home. As a by-product of the overcorrection programme, some demonstration was made of the role that staff interactions had in promoting cooperative or oppositional responses by Linda. This may have helped in setting

the scene for the success of the far more acceptable programme of management that followed.

Positive developments and the role of the house

While wishing to describe in detail the possible errors in judgement and difficulties that the service has experienced, we do not wish to suggest either that there was nothing good to say about this period or that a residential service with other characteristics or objectives would necessarily have served Linda better. We do not know. It is possible to conceive that if Linda had been provided with a residential arrangement made specifically for her, so that her needs were not constrained by the requirement to also meet the needs of others, her programme of care would have been improved. But the provision of more specialist care is, even today, still confused with the provision of specialist "units" which group people together who are said to share similar characteristics. Linda might be regarded as one of a group which is often singled out for special definition: people who are severely socially impaired, non-responsive, and who engage in ritualistic and other inappropriate behaviours. However, grouping together people who are said to share particular characteristics does not in itself constitute the provision of a specialist service, and it does have some undesirable consequences. Grouping a defined minority of people together implies larger catchment areas and the breakdown of local services. It also implies creating a very different social environment which is defined by the prevailing similarities between group members. It is not logical for the service to create such a social environment unless it is the long-term objective of the service to support its continuance. If not, the creation of such an environment simply compounds the extent of change which must be generated. The objectives of care underpinning the 10 Summerton Road service were consistent with the creation of a normal social existence. However, the extent to which it could achieve that objective has been limited by the number of people and the range of individual needs it sought to serve. Further development is called for: of service models which are smaller in scale, more extensively individualised, and thereby *specialist*.

Even during the unsatisfactory period of confusion and difficulty for Linda, certain positive goals were being achieved. By and large the needs of Linda's relatives were being met. Their

daughter had a residential place in a local house which they considered to be well-staffed and to have high material standards. They recognised the positive ethos of the service and trusted it to act in Linda's interests. They were involved in making decisions concerning her care programme through the individual planning system. They believed Linda to be happy at the house; and Linda's sister often expressed her relief that 10 Summerton Road was there, particularly during the times when she was in America. The fact that the service was local had enabled them to maintain a considerable involvement in Linda's life, having her home to stay frequently and as much as they wanted. They also saw that the service was seeking to give Linda responsibility and to develop her involvement and contribution, something which they began to copy when Linda was with them.

Even though the frequent changes between living at the house and living with her family may have confused and unsettled Linda, the importance of her continuing relationship with her family should not be understated. The proximity of the service and the openness and ease with which contact can be arranged means that Linda can see her family regularly. She stays with them every other weekend and they visit her on the alternate weekends. She visits their house for tea on the Thursday before each weekend she stays at 10 Summerton Road. Her parents 'phone her and she 'phones her parents. Not only do her parents and sister get Linda more involved in their household routine when she stays with them but they also join in her activity when they visit 10 Summerton Road.

Successful teaching has also occurred. Linda has one of the highest success rates in the formal skill teaching programmes set. The pattern of staff interaction stressed in the formal teaching session is the same as the staff interaction procedure used routinely to gain her attention and cooperation. Since moving into the house permanently she has learned to prepare a bath and bathe independently (with intermittent checks from staff), to brush her teeth, to make sandwiches, and to prepare cheese on toast. A monitoring system on the range and extent of Linda's participation in household activities was introduced shortly after she had settled in the house. At first, she was involved in about 28 household tasks per week. Now she is involved in about 40, reflecting a growing level of participation in the life of the household. It is true that other people living in the house may have

double that amount of involvement and some, who do not go out to day-care services, treble that level of participation, but the records reflect the staff feeling that constructive occupation is on the up for Linda as well.

Linda has lost weight, from between twelve and thirteen stones at the outset to just over nine stones. This has helped to make quite a substantial change in her appearance. Perhaps because her clothes pull less, the habit of pulling and flicking up the back of her dress when getting up and walking has decreased. The reduction in weight has also enabled her to wear trousers.

It is still true that Linda has fewer opportunities for community involvement than others in the house. Our concern to address the issue of her self-stimulatory noises and movements was motivated very much by the knowledge that they acted as a barrier to using community amenities. For example, she went to pubs less frequently than others living in the house and, when she did, the tendency was for her to sit in the garden where her behaviours could be better tolerated than in the bar. Mistakes have been made in trying to find suitable activities for her to pursue in the community. For example, an attempt was made to take her to the cinema. Linda and the member of staff deliberately arrived just as the film was to start. A bag of pop-corn was purchased to provide Linda with a source of activity that it was thought might compete with her "amping" noises. However, she was very noisy in taking her seat and continued to shout a great deal during the opening titles. Moreover, on being given the open bag of pop-corn, she threw it the length of the cinema, spraying out the contents as it went. At that point, they left.

At the same time as the problems of management inside the house were occurring, Linda began to be incontinent quite frequently when in the town centre. Her trips to shops were curtailed. However, as improvements were brought about within the house and in the special needs unit, a programme for reestablishing community involvement was followed. At first, Linda went for short walks with staff in the roads around the house. As these were managed successfully they were gradually extended until she could again take walks to the town centre and back. A beneficial by-product of this deliberate programming was that Linda learned to walk without holding someone else's hand, another contribution to making her a less conspicuous person when out and about in the neighbourhood.

At the moment, Linda's problem stereotypic behaviour appears to be reduced and the prospect of widening her experience of life in the community appears better. Her use of language is now more extensive, she is easier to live with and talk to. She knows the other people who live in the house with her and shows them consideration, sharing things, or passing items at the meal table. It is possible to see different relationships forming between Linda and different members of staff. She likes to know who will be on duty when she returns from the special needs unit and this information is passed on by the house staff so that they can tell Linda when she asks. Some of the beneficial developments experienced by other members of the household have been shared by Linda. A gradual process of fostering pro-social behaviour to the exclusion of her inappropriate conduct has achieved some success and has ensured Linda a local place of residence. We still wonder whether, because of the difficulties involved, we avoided dealing directly with her preference for self-stimulation and her consequent tendency to avoid learning situations and opportunities for participation in general. Whether this avoidance has had, and is continuing to have, a deleterious effect on the situation in which Linda finds herself is still a question which nags us.

REFERENCE

Knowles, W., Masidlover, M. *The Derbyshire Language Scheme Teaching Manual.* (Private publication.) Ripley, 1982.