CHAPTER 8

Concluding remarks

Life goes on

We have described something of the life of one house and nine people with severe and profound mental handicaps over a period of three years. In its relevance to the development of community-based services, it was a critical three years; the initial period being one of the first attempts to look after adults with such a degree of disability in ordinary houses, including some who had been considered disturbed for much of their lives. Eighteen months has passed in the preparation of this book and, although people's stories have continued, we have decided to keep our description within its original boundaries. However we think that a brief sequel to some of the accounts is valuable.

We summarised our concerns about how successful the service had been for Linda by saying that it took a long time to get to first base. Events in the last eighteen months have confirmed this to be true. Linda has begun to experience the kinds of development that have been described for other people. She is more settled now that she lives permanently in the house, but retains an active and good relationship with her local family. Even though staff think she may still prefer to live with her parents, she now clearly lives at 10 Summerton Road. She is involved in the life of the house as a contributor. She talks more, has friends among the staff, and cooperates more easily. She has lost weight, is fitter, and her appearance has changed considerably. She and her family attend her individual programme planning meetings and service staff and family members have good working relationships. Of course, we do not wish to give the impression that all is transformed. Linda requires considerable support and still leads a fairly sheltered life. She also still has many challenging behaviours. We will return later to the absence of long-lasting "cures".

One of the ingredients of life in general is its unpredictability; stability can never be guaranteed. Shirley's job was no more secure than paid employment is for any other member of the working public. The small brewery that operated the pub which she cleaned went out of business, as a result of which she lost her

job. Like other unemployed people she has to look for a new job. Unlike other unemployed people she is almost entirely dependent on staff help to do so. The fact that Shirley had a job made it easy to convey to others that her life had changed dramatically. When she lost it, we no longer had that easy route to encapsulate the impact of the greater opportunities Shirley has had since moving from hospital. Nonetheless, the change in her home life was dramatic. She has recently found another job.

Catherine's development has continued in the last eighteen months. The joint effort of her parents and the house staff have brought considerable benefit both to Catherine and to themselves. No new directions have been undertaken but the progress that has been made seems more secure. For a long time we lived with a considerable feeling of vulnerability, fearing that the progress could be lost. Catherine will always be profoundly mentally handicapped and she may still threaten to take her clothes off. But there is a feeling that the development she has achieved has given her sufficient pro-social means of influencing those around her that she will continue to live in a situation which has at least the advantages of 10 Summerton Road if not, in time, something better.

Common themes

It became clear in setting down the detail of each person's story that a number of themes were common to all accounts. The implication is that people with mental handicaps share common experiences whether they have lived in institutional care or the family home. These might be summarised as: limited community participation, to an extent that could be characterised as a failure to achieve citizenship (in its most extreme form, segregation can result even in the loss of community presence); low status and the failure to achieve adulthood; limited support and exposure to opportunities to develop in competence; and a lack of protection of rights and personal interests. The last of these may include failure to receive the kinds of treatment most of us take for granted, such as dental care and prescription of spectacles, or the absence of access to a wide range of activities and experiences which are the stuff of life itself. People who are substantially handicapped typically experience a life of low demand, little expectation of contribution, and no responsibility. This is often equivalent to a life of little variety and low external stimulation; a

life which most people would generally perceive as empty and of little interest.

Any service which strives to have impact on these areas of deprivation will therefore need to be active on many fronts if it is to deal with the particular issues relevant to each individual. It is fairly certain that there will be no shortage of ways by which a service *can* act to improve an individual's competence, status, social activities, community participation and contribution, access to treatment and education, and the breadth and intensity of day-to-day activity and experience. If services face the challenge of helping people with substantial handicaps to achieve a life style and a lifetime of experiences similar to those enjoyed by people who are not handicapped there is a huge agenda of work to be done and effective methods to be developed and learned. The task is overwhelming and it is therefore common for services to set objectives only from a relative standpoint: to be generally better than what went before and for an individual to do something different or more than previously.

The service we have described cannot, by any stretch of the imagination, be considered ideal; one which gives the people who depend upon it a fully valued role and position in their local community. By relative judgement, however, it has made some strides towards: re-establishing a community presence for some people and allowing it to continue for others; promoting a life of greater personal responsibility and contribution within the house; promoting a wider variety of interesting or potentially interesting participation in activity; promoting competence, although probably more by a wider application of skills already possessed than by teaching genuinely new motor and cognitive responses; and improving the social status of all of the people described by conspicuous effort to gain a smart, adult appearance and by detailed attention to the content of their activity. (For example, the service users may be perceived as economic contributors to the local community because they do the shopping and pay for the goods purchased, albeit with staff help.)

The area of community participation still has a low level of achievement. The service and its staff have done much which is within their direct power to achieve. In its location, its determination to serve people from the locality, and in its mode of operation, the service has attempted to provide the best possible opportunities for continued or re-established contact between

people who have come to live at 10 Summerton Road and their families. Staff have supported members of the household in a high frequency of community use: shopping, using leisure amenities, and going to pubs, cafés, and restaurants. The people living in the house during the last year that these stories cover had, on average, 111 family and friendship contacts; the range being from twenty-three for the person with the least frequent contact to 260 for the person with the most. Contact took the form of people visiting the house, or people from the house going out during the day or for overnight stays away. In addition, people from the house went out to shop, go to a pub, restaurant or café, or to use other community facilities, on an average of 228 occasions in the year, the range being from fifty-two to 415. However, friendships outside of family or staff remain limited and people's contact with the general public is almost entirely at a casual acquaintance level; a few fleeting interactions while shopping or the like. Staff have made efforts to encourage friendships but they are hard to achieve, certainly with that essential element of reciprocity of interest, power, and value which characterises true friendship. Achievement is not entirely absent. Mary has developed friendships and Shirley has visitors who are not immediate family; but it is an area of limited success which may be more closely related to the nature of the service than to the staff's efforts within it. It is still a segregated service in which people with mental handicaps live exclusively with other people with similar handicaps. It is still a service which provides for a relatively large group of people, spanning a considerable range of personal characteristics, competencies, and aptitudes. These factors may constitute considerable barriers which limit the opportunity and basis for the flowering of close personal relationships; ones which add to the barriers inherent in the real functional handicap of the people being served.

Complexity and specialisation

While recognising that problems are still evident in the service, it is important to acknowledge the considerable complexity of issues which staff have attempted to address, and which have been met with some degree of success. What is remarkable is that, at any one time, this span of concern is in the hands and heads of only one person-in-charge, one deputy, and seven other day-time staff. Staff need skills of household organisation, observation and

interpretation of behaviour, clarity of statement, teaching, task analysis, routine supportive interaction, talking to people who have difficulty in comprehension and articulation, discussing with families, liaising with other professionals, and demanding action from others in the best interests of the people for whom they are caring. It is not an easy job and they receive scant reward for their expertise. Our aspirations for what can be achieved have grown: there is a growing technology for behavioural analysis and development which needs to be widely mastered: our expectations of what staff must achieve have risen accordingly. Our service structures, however, have not changed to any great extent to allow staff working directly with people with mental handicaps to be rewarded either materially or in terms of status attribution for the specialist expertise they supply.

In looking at the wider service structure, it is also true to say that the responsibility for service quality lies more with the staff than with the managers or providers of the service. Take our concerns about Linda and whether the service was acting in her best interests as an example. These concerns were confined mainly to the service staff. They were not initiated by Linda, by Linda's parents, by any person external to the service who had taken an advocacy role on Linda's behalf, or by the managers of the service. It was satisfactory in all these quarters to continue the *status quo* through a strategy based on containment and working round the problems. Another example is that, in order to do their work effectively, staff need to collect certain information on the experience of each person living in the house, routinely, individual by individual. This monitoring covers the implementation and success rate of teaching, the opportunities given to each person to be involved in household life, and the extent of each one's family contact and use of community amenities. These data give staff a basis for reviewing what they are achieving on behalf of each person. Recording, however, takes time and discipline. Keeping the recording going is largely down to staff diligence and pride in their own rigour. Were they to stop it, it would be interesting to see whether people outside the house would find out that part of the service programme had been dropped.

Not only is the quality of the service largely in the hands of these front-line staff, so too is the safeguarding of service quality. This should not be taken as a criticism of the service managers but as a statement of concern for a vulnerable situation. The manager's

position can be appreciated. Relatively few people are being expected to plan and provide the new services which are to replace existing institutions. They are also expected to do this broadly within the expenditure framework of the previously impoverished service. They are expected to establish new modes of operation, train staff, determine the allocation of finance, and be accountable for public expenditure. Some recognition is needed of the complexity that is being demanded of them within a modern definition of accomplishment.

The view we have put forward is that there is a considerable degree of specialism needed within the service staff. We have not defined that specialism in terms of the traditional professional boundaries: psychiatry, psychology, physiotherapy, speech therapy, occupational therapy, and nursing. We believe it is important, however, to stress that we *do* see the business of providing such services as an area of specialism because of an all too common confusion that what is required is ordinariness. The notion of "ordinariness" has been appealed to by people trying to encapsulate the direction of development which residential services should take. However, ordinary, as a descriptor of a life style to be made available by dint of service activity, is very different from ordinary as a descriptor of service process. The former suggests a characterisation of activities, responsibilities, and relationships which, although allowing for a considerable variation in precise detail, might encompass the broad mass of citizens in our society. The latter suggests a limit to the intensity of resources, time, expertise, and service structure which might be directed towards helping a person achieve a desirable outcome. Staff working with people with severe and profound handicaps need to be particularly skilled if they are to make available to these individuals the possibility of a reasonably ordinary life style. For example, one of the classes of staff expertise which is of considerable sophistication is the ability to structure an individual's experience carefully so that the person derives benefit, but without the structure assuming an intensive and conspicuous presence.

One last point concerning the nature of staff specialism. Skill deficiency relative to age is the objective fact upon which the inference of mental handicap is based. As it became apparent that even people with extreme deficiencies were capable of continued learning, service objectives changed from those defined as

custodial to those defined as habilitative. The model of service process changed from care to education (although this has not been accompanied by a change in dominant professional groupings). However, although philosophies of education may vary, skill acquisition is not generally seen as an end in itself. Rather skill usage and the growth of experience are more fundamental objectives. Habilitation (skill-acquisition) is a relatively minor component of this service and teaching a similarly minor part of the staff specialism (although the skills involved in teaching are related and extremely relevant to those involved in supporting adaptive behaviour generally). In nearing the end of this book, we are aware that readers may have perceived the central contribution of the house to people's lives as being in the area of skill acquisition. We think that it has been part of the contribution, but that the major part has been the supporting of a wide variety and extent of adaptive participation during every day of the three years covered, where passivity, unpurposeful activity, and inappropriate or damaging behaviour could so easily have been the alternative. Even in this account, progress stands as a proxy for day-to-day participation; it is easier to capture and describe.

Keeping going

The quality of a service is concerned with what service-user behaviours it actually promotes and the means by which it does so. An individual's behaviour is flexible; it changes in response to the current situation. The individual reacts to the current situation from an accumulated history. That accumulated history cannot be taken away. It cannot be eliminated in the same way as an invading bacterium can through the taking of an appropriate antibiotic. Cure is the wrong metaphor.

What we have described in these pages is largely the influence exerted by a service on the way a number of individuals with severe and profound mental handicaps have reacted. The influence has been brought about by changing the situation in which these individuals have found themselves. Considerable experience of such a changed situation may in time alter the balance of accumulated history and the predisposition of the individuals to react in certain ways. But three years, even if people had attained a consistency beyond what in reality has occurred, is a relatively short period compared, for example, with the twenty-

two years' prior experience of life that Catherine had known, let alone the half-century of different circumstances for Carol.

If cure is the wrong metaphor, perhaps another can be offered: in order to arrive at the right port, the current course has to be maintained for however long it takes to get there, making adjustments for tides, currents, changing wind direction, and storms along the way. Maintenance of service quality has to be arranged by the service; reliance should not be placed on the constancy of the behaviour of the service user. For example, despite being generally more cooperative, Linda still challenges staff by disarranging the house. Carol too has recently increased the frequency of biting her forearm again. It would be wrong to conclude that past efforts have failed. Past efforts, as we have reported, have been successful in establishing a decline in specific behaviours and a growing maturity or level of cooperation. However, they could not be expected to result in change that would be sustained for the rest of people's lives. Staff now need to look again at how they are interacting with Linda and Carol. They may have failed to maintain in their own behaviour a pattern of interaction which was relevant to the previous success; a fact made more likely by staff turnover. It may be that greater precision is required; a precision which is attainable by repeating the analytic process which worked before. Like any other form of activity, practice improves skill and precise definition concentrates analysis. The problem is that this need to retread familiar paths may lower staff morale if their model of human behaviour suggests permanent solutions without the possibility of future regression. At its most extreme form, interpretation that previous intervention failed because it did not result in permanently enduring improvement may prevent staff re-adopting successful strategies. Staff may lose direction if they lose faith in operational procedures and have no better explanations or perspectives to put in their place. Services should be seen as always being vulnerable to deterioration, and the quality of service operation needs therefore to be maintained by appropriately responsive management, in much the same way as staff fulfil their responsibility for the behaviour of the people in their care.