CLOSE TO HOME:

a local housing service and its impact
on the lives of nine adults
with severe and profound mental handicaps

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Sandy Toogood

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Dedication

To Harry McCree, whose
authority and effort allowed the service
to be developed

Contents

Page

Acknowledgements 6

Chapter 1. Introduction — about this book 7

Chapter 2. Shirley White — a new home and out to work 20

Chapter 3. Catherine Henderson — avoiding institutional care 48

Chapter 4. Mary M . . . — family contact is not the only consideration 83

Chapter 5. Carol Brown — developing independence in familiar surroundings 107

Chapter 6. Richard Oliver, Margaret Tarrant, Elizabeth Shaw, Kathleen Wright — a variety of issues 125

Chapter 7. Linda Chandler — some successes, some failures 163

Chapter 8. Concluding remarks 184

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We hope we have recorded facts accurately. The perspective and opinions are ours, as are any errors.

David Felce
Sandy Toogood

CHAPTER 1

Introduction — about this book

This book is about one ordinary house in a residential street near the centre of a small market town, called for the purposes of anonymity 10 Summerton Road, Merton. It has been home for nine adults with severe or profound mental handicaps who have local ties. It has also provided the setting for a research project designed to investigate ways of running this kind of residence as an alternative to large mental handicap hospitals. Although the suggestion of community-based alternatives to institutional care is not new, few such schemes exist for adults with the most severe handicaps who are in need of residential care. There is still some controversy about the desirability or feasibility of schemes of this kind, hence the relevance of continuing research and development.

The research programme included setting up the house and working closely with staff in how to run it. A research evaluation was also carried out, using various objective indices, of the day-to-day life and activity of the adults for whom the house became a home. References to the various evaluation reports are given at the end of the chapter.

This book, however, contains a different kind of account. It is a factual description of the story of the house, told through the experiences of the nine adults who lived in it. It is our perception of the human stories behind the research. Although the book concentrates on the experiences of individual people, its overall theme is the house and the orientation of the service; for, despite the detail, it is inevitably an account written from our viewpoint as service providers. The adults whose lives are described largely lack language and so cannot give an account of their own views or feelings, explain their own behaviour, or say what they would like to happen in the future. We have tried to maintain an impression of observing their lives from the outside rather than appearing to put forward opinions or interpretations as if they were their own.

It is important to keep in mind that the descriptions cover only a short period in the lives of the adults concerned. Parts of each person's story have been selected and discussed; parts which seem to have special relevance in relation to issues commonly raised in

the current debate about residential services for adults with severe or profound mental handicaps and disruptive behaviour. Throughout this century adults with disabilities of this kind, particularly those whose behaviour is considered aggressive, asocial, or strange, have been accommodated in segregated institutions away from the villages, towns, and cities in which most of us live. Slowly the climate has been changing and there is now greater support for the notion that everyone, unless found guilty of a criminal offence, should have the opportunity of living within the community in an ordinary residential area, and of experiencing the normal patterns and responsibilities of daily life. But, as with any process of social change, there is always a debate. Questions have been raised in connection with the practicality of implementing the community care policy: "How can adults with such severe handicaps live a normal life in the community?"; "How can difficult behaviour be managed?". There have also been questions about whether there are any advantages to the adults concerned: "How much will someone with a profound handicap respond to a normal pattern of life?"; "Isn't the tranquility of a sheltered institutional life more suitable for adults who cannot cope independently with the stresses of modern society?".

Before beginning our account we must declare our own view of the development of human behaviour. We think it can best be understood by looking at the day-to-day interaction between the personal characteristics of individuals, their current situation, and what they have learned from past experience. So we would not look for answers to the above questions just by studying and classifying the personal characteristics of people considered to be mentally handicapped, or by cataloguing differences between various types of environment and making assumptions about how they may affect behaviour. We think that the answers to these questions can best, and perhaps may only, be found by gaining experience of different types of service alternatives and finding out how each one benefits or fails to benefit the people it serves. Take the question: "How can difficult behaviour be managed?". We think the best chance of finding out the answer is to design and implement a service which attempts to do so, and to learn from the successes and failures experienced along the way. Little will be learned by excluding from the start people with difficult behaviour, on a prediction that they may not be managed. From

our standpoint there has been too much rhetoric and too little development to date; too few practical attempts to test alternative ways of providing residential services.

It seems to us that the debate on this major change in social policy is still being conducted on the whole in vague, imprecise statements, with little empirical evidence being brought to bear on the validity of the propositions discussed. We wrote this book, therefore, because we thought a useful contribution to the debate would be as careful a description as we could manage of the personal circumstances and experiences of some adults with severe and profound handicaps and how those changed when the service provided for them was changed.

Research has tended, in the name of objectivity, to avoid detailed personal accounts. As people involved in research, we do not wish to belittle the importance of objective evaluation. We believe scientific method is crucial to the development of social policy. The credibility of the accounts given in this book would be diminished if we were not able also to list a series of research reports at the end of this Introduction which attempt to follow the rules of scientific methodology. However, we also believe that much of the *quality* of the change in the lives of the adults who have lived at 10 Summerton Road would go unrecorded if we had restricted ourselves just to reporting the information gathered by the objective research measures employed. Although our research data are important to us, it was the *quality of the adults' experience* which these data reflected that gladdened our hearts and encouraged us to believe the service was developing in the right way. When we interpret our own research data we have concrete pictures of real people doing real things as they go about the business of their daily life. Our reason for writing this book is to attempt to help others view the service development, and the research of it, through the eyes of those who have been closely connected with it.

Words of caution

This book is a record of the accomplishment of a single service setting in terms of the change it brought about for a few adults with handicaps. It shows what is possible; it illustrates an orientation; it highlights where improvements are needed and where problems still exist. However, there are dangers in over-generalising or simplifying. There need to be many more examples of high quality

services and further work on what distinguishes a high quality service from a mediocre or poor one before we can be satisfied that such services can be delivered routinely to those who need them.

The house described is an example of a new type of service. If new services are to be different from those that have gone before them, they must be operated in different ways. This necessitates competence in new areas, and it is likely that the skills required in providing community-based services for people with the most severe handicaps will be relatively thin on the ground for some time to come. The growth in high quality residential services, therefore, may need to be gradual. Also, the specification of such a service is complex. It involves aspects of size, building design, location, staffing, operational policy, job descriptions, management relationships and support arrangements, staff training, and working methods. The residential service to be described is not just an ordinary house in the community, although that is part of it. Simply establishing a small community residence using ordinary housing, but without the careful arrangements made in other respects, would not necessarily have similar benefits.

Although the accounts given in this book are lengthy and we have tried to be both detailed and precise, the information contained is selective. Our interpretation of some of the information, and our analysis of why people's behaviour changed, is opinion. It may be considered thoughtful and convincing by some readers and not by others. Although one author is a research scientist and scientific evaluation of the house and the adults is available, this does not mean that the accounts given in this book are scientific. For example, the fact that we have precise measurements of the rate of change of some disruptive behaviours does not mean that we know for sure why the behaviour changed. Proof requires appropriate (and ethical) use of experimental design, in addition to measurement and careful interpretation. Unfortunately some useful research on individual change was beyond our resources given the other types of evaluation we were conducting; thus, the majority of our explanations of change remain speculative.

We have tried to be thoughtful and honest in our accounts and to fit our knowledge of what was done by service staff to our knowledge of how it affected the service users. In doing so we have brought to bear our knowledge of the scientific literature on how

people's behaviour may be affected by their environmental experience. We have not attempted to cite the literature, but rather to concentrate on telling an uninterrupted story. Our understanding of human behaviour is derived from the literature of applied behaviour analysis. However, we do not profess to have a complete knowledge of this, or an indisputable interpretation of it. Moreover, it is certain that some of our interpretation is wisdom developed after the event. Neither we nor our service colleagues were always quite as smart or certain as the impression given in the pages which follow.

It is, however, true to say that we had a commitment to making community care work. We hope that the difficulties and problems, as well as the successes, are adequately reflected in our descriptions, so as to make the accounts given true-to-life and to convince readers of our honest endeavour to describe accurately what really happened.

About the house

We sought to establish at 10 Summerton Road a residential service which set out to achieve a clearly defined purpose. As it was an intensively staffed service for people with severe and profound mental handicaps this meant concentrating on how staff did their job. We tried to influence this by establishing procedures for staff to follow and by providing specific staff training. The house, as a service, can be represented by three strands: its orientation, its structure, and the staff procedures followed.

The stated orientation of the service was defined once the prime function of the house in the lives of its users had been determined. We considered how ordinary people typically conduct their lives, and how having a mental handicap might alter their experience. We decided that the prime function of the house as a residential service for adults with severe and profound handicaps was to provide people with a permanent home; therefore, the primary aim was to open opportunities and give support to the people living in the house so that they might experience a "normal" pattern of home life. This pattern was to include contribution and responsibility as well as comfort, leisure, security, and close social relationships. Specifically, we thought that one of the major experiences of people with such severe handicaps was a difficulty in being fully occupied and stimulated throughout the day in activities which usually preoccupy those of us considered to be

non-handicapped. Our central objective, therefore, was the provision of opportunity, choice, and support, which would result in the adults being meaningfully occupied for the bulk of their time. It is only when such an objective is achieved that leisure and rest can take on their true meanings.

Another specific objective was for the adults to continue to develop skills and independence as a result of their experience of the service. Moreover, it was intended that the service would be competent to alter patterns of socially inappropriate, damaging behaviour, and replace them with more constructive alternatives for the benefit of the individuals concerned. Lastly, home life was seen within a social, community context. Community integration was a specific aim, embracing the use of the amenities of the local town, the maintenance of family ties, and the development of friendships and personal pursuits outside of the home.

The task, then, was to provide a service structure which facilitated these objectives. We wanted the physical design, location, staffing, and organisational arrangements of the house to reflect client considerations rather than traditional or bureaucratic structures of the service-providing agency. We wanted to ensure that, unless specialist service arrangements were known to enhance the quality of client experience, the adults living in the house would share the arrangements chosen by the broad mass of the population. We wanted an efficient organisation, and one in which the staff on whom the adults depended had few obstacles placed in their way, so enabling them to make all sorts of beneficial arrangements for the individuals they served. We wanted a local service so that families and friends were nearby; and we wanted the house to be as close as possible to the centre of town to enable maximum use of its amenities. We found that it was possible to achieve many of these objectives within the constraints of the service providing agency, the National Health Service.

The house is a four-bedroomed, detached property sited among other similar houses in a residential street close to the centre of Merton. Conscious efforts were made to maintain the appearance of the house as a private dwelling but two additional bedrooms and an extra bathroom were added to the ground floor at the rear of the property for the benefit of adults who could not manage stairs. There is a mature garden with lawn, flower borders, and established shrubs. Decoration and furnishings are to a standard that would be expected in a well-to-do home, and equipment and

household effects are geared to giving the impression that the house is simply the home of several ordinary, mature adults. No extra safeguards against accidental damage or injury are built into the physical environment, and the adults have access to domestic appliances, electrical equipment, and breakable ornaments. The onus of ensuring the adults' safety and exposing them to only a reasonable level of risk is placed on staff. The expectation is that people can care for themselves and their surroundings if they are given sufficient support to enable them to undertake that responsibility.

There are still some obtrusive features, mainly to do with safety against fire, but many common problems in the appearance of service buildings have been avoided. Instead of vinyl, the living room furniture is upholstered in cloth; the kitchen is fitted with ordinary wood and laminate units; and the cooker, refrigerator, and other household appliances are domestic rather than commercial models. The living room, hall, stairs, and bedrooms have wall-to-wall wool-mixture carpets. Ornaments, plants, and other personal decorative touches abound. Despite the rather large number of people living in the house, its appearance has been well-kept over several years.

The house provides eight residential places and, therefore, its inhabitants still live in a large group by normal standards. At first two places were reserved for short stay provision for people living nearby with their parents. This was contrary to our original intention but had been requested by the representatives of a local voluntary society. Later, this was reduced to one place. There are 11 whole-time-equivalent staff posts, nine day staff and four half-time night staff. Within the allocation of day staff are included the person-in-charge and the deputy. There are no separate cooks or domestics as it is intended that the adults have every possible opportunity to participate in the daily round of household chores which their lives generate. The staff have considerable freedom to manage their day-to-day activity. They have control over budget expenditure, which is vital if they are to be free to shop with the adults and arrange for the upkeep of the house and garden. However, given their autonomy, careful effort has been given to staff training and the structuring of working methods.

For every theme in the statement of orientation, we wanted to design a staff procedure explicitly directed towards attaining that objective. The theme of individual development is reflected in

systems of individual programming. *Individual programme planning* (IPP) meetings (Jenkins *et al.*, 1988) give a comprehensive review of the priority needs for each adult to which the service should address itself. These encompass needs for wider experiences, improved health, improved or more mature appearance, learning, friendships, wider pursuits, and greater community involvement. The meetings comprise a multi-disciplinary group of professionals, each of whom has an active role in the care of the adult being discussed, together with the adult and the adult's relatives or advocate. Health and social services personnel set objectives for each adult together.

Where educational goals are concerned, programming within the house is conducted at two levels of intensity. In a "broad-brush" approach, which we term *opportunity planning* (Toogood *et al.*, 1983), several (6-10) behavioural objectives are set for each adult every fortnight and written on a single chart which contains a recording grid spanning the next 14 days. Staff build in opportunities to practise each behavioural objective during the adult's day and record implementation and success on the grid. Opportunity plans do not specify the method of teaching but they do ensure that, irrespective of which staff are on duty, emerging skills that need to be worked on every day are targeted and recorded. At a more detailed level, staff also set and follow individual teaching programmes, using the *Bereweeke Skill-Teaching System*. Skills to be taught are analysed into a series of discrete weekly steps, each one of which is then programmed on an activity chart. The activity chart sets out the teaching objective for the week, the method of teaching and the number of teaching sessions per day. A record shows implementation and the adult's progress towards the goal. This more intensive level of teaching is used for goals where staff have already experienced (or predict) lack of success with opportunity planning. The *Bereweeke System* materials have recently been revised in a second edition (Mansell *et al.*, 1986) which includes a staff handbook, and assessment checklists for children and adults. The checklist for adults (Felce, *et al.*, 1986) has been specifically designed to translate early developmental skills into activities which are appropriate for adults rather than children.

Skill acquisition as an objective for people with mental handicaps is rarely questioned, presumably because it reverses the defining condition. Skill usage, or engagement in activity, is the

important consequence of capability, however, and this can be viewed as a fundamental indicator of the quality of a person's life and of the care given. The service environment (including the pattern of staff activity) can be said to be appropriate for someone to the extent to which it supports the translation of that person's skills, however limited, into meaningful activity. Choice can only be said to be present if the environment provides the support to create real opportunities for individuals to participate productively. Important though individual planning and teaching are, the proportion of a person's day which is spent following a written programme or an activity derived from a plan is low. This is not necessarily a criticism — it may actually be appropriate for adults, for whom some balance between continuing to learn how to live life and actually living it should be drawn. Therefore, if following individual programmes is going to be a small part of a person's day, what remains of the utmost importance to overall service quality are the routine interactions and orientation of staff. How much do staff support individuals' involvement? Which behaviours of the people in their care do they motivate? How much opportunity do staff deny people with mental handicaps by doing tasks themselves? However sophisticated individual programming may be, it may be of little account if these general aspects of staff performance are poorly determined.

Procedures have therefore been established in the house to help staff take a systematic approach to the routine organisation of the adults' day and the allocation of household tasks and caring duties throughout their time on duty. Promotion of staff performance has involved three strategies: establishing a basic organisational structure; training staff in the philosophy of the service and means of promoting the adults' independence and participation in events and activities; and establishing a form of monitoring by which staff can review how successful they have been in supporting the adults in a range of community and household activities. Parts of the staff induction training cover organisational structures at a very simple level — how to organise shopping, cleaning and cooking, staff rotas, communication systems, and household standards. Staff training also covers the behavioural principles of staff:adult interaction, including the use of antecedent conditions to help to encourage adults' engagement in activity and learning situations throughout the day. Instruction, demonstration, physical prompting and complete physical guidance, paired with the task

analytic skill of breaking a complex behaviour into small, discrete stages, is used to help people with even the most severe handicaps to participate effectively.

Staff interaction with the adults is an important motivating factor. Attention, particularly praise, should be directed towards adults' meaningful occupation as opposed to passivity, or unpurposeful or inappropriate behaviour. Even though this may not always be sufficient to motivate adaptive behaviour in the adults, staff awareness of how they distribute their attention remains a desirable general accomplishment. Day-to-day organisation and planning of adults' activity is achieved by a flexible system of timetabling and allocating staff responsibility, which also involves staff in recording and summarising the activities in which each adult participates within the household. Like other monitoring mechanisms incorporated within the methods of care (such as the implementation and success rates of teaching in the *Bereweeke* system and the recording of community events), this provides feedback data for review of care practices in the weekly staff meetings.

About the chapters

Nine adults have lived in the house from its opening to the time of writing, a period of over three years. Five were involved with the service at its start and a chapter is devoted to each of their stories. These chapters share a similarity in format because, although concerned with different people, they illustrate the response of a single service to the diverse needs of each individual. Overlap between the chapters reflects the common experiences of people with severe handicaps: the tendency towards childish appearance, low expectation, absence of responsibility, lack of opportunity for participation or development, and the likelihood of strange or anti-social behaviour being interpreted as deranged or deliberately oppositional rather than sensible from the individual's viewpoint. Each chapter concentrates on the service response to an individual; a response which seeks to enhance social status by helping each one achieve an appearance, responsibility, and degree of participation in daily life that is appropriate to that person's chronological age, irrespective of mental age. This response also assumes that, within their current capabilities, people with mental handicaps are wise, and their behaviour serves a positive function. If the service is to be wise,

that is, if it is to help its clients to develop new ways of behaving which are more advantageous to them as individuals, it will need to seek to understand their wisdom.

Service responses are largely determined by the personal characteristics of clients. Each chapter, therefore, contains some description of the adults whose stories are being told. Some readers may feel that these descriptions are clinical appraisals; pictures of how people present as "problems" to the helping service, devoid of human warmth. Simple explanations are often the best, and the simplest here would be that we lack the novelist's skill to conjure an accurate picture of each person. But other thoughts are relevant. It is important to convey to readers what the adults did or did not do, and how they each chose to spend their time, for this is how service staff experienced them. A metaphorical description based on personality traits does not do this. It also fails to capture the impact of having a mental handicap. People with severe mental handicaps have personalities: they may be cooperative, enthusiastic, highly sociable, charming, withdrawn, self-reliant, awkward, or whatever. What is not conveyed by these terms is the means by which those people express their personalities. Personality traits can be expressed through behavioural abilities which are completely beyond the people described in this book. It is relevant, both to the understanding of the significance of the service response and to the place that these accounts have in the debate on service design, that readers gain a correct impression of the lack of ability of the people described. Their lack of communicative language for other than basic needs constrains our descriptions as we have no direct access into their views on life, likes, dislikes, or preferences. We have tried to refrain from expressing our own thoughts as if they were the views of the adults or an indication of their personal characteristics.

As there is so much common ground in the experience of many people with mental handicaps there is a danger of repetition from one chapter to the next. We have therefore been more selective in describing the stories of the four people who have spent less time in the house. We have concentrated on a particular aspect of each one's experience which we think may have some general relevance.

The material in all the chapters, both in terms of the adults' experiences and the service responses, can be related to issues of

service philosophy. Occasionally we interrupt the narrative to explore such issues further. We hope that readers who wish to continue the narrative at these points will excuse our digressions.

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