Development and evaluation of innovative residential services for people with severe intellectual disability and serious challenging behaviour

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I Introduction

In many Western countries, services for people with intellectual disabilities have been transformed over the last 30 years, as institutions have been replaced by residential services in the community (Mansell & Ericsson, 1996). Although generally successful, leading to better outcomes for the people served on many indicators, deinstitutionalisation and community living has been problematic where service users have had complex additional problems such as challenging behaviour (sometimes called problem behaviour). People with challenging behaviour are less likely to be offered community services until the end of the deinstitutionalisation process (Wing, 1989). They are more likely to be re-institutionalised (Intagliata & Willer, 1982; Pagel & Whitling, 1978; Sutter, 1980), with some deinstitutionalisation programs placing significant numbers of ‘difficult to serve’ people in other institutions (Mansell, Hughes, & McGill, 1994a).

As Felce, Lowe & de Paiva (1994) point out, these difficulties contribute to the view that there is a continuing need for institutional provision for people with challenging behaviour. At the same time, institutional provision for people with challenging behaviour continues to be problematic. Individuals who have serious challenging behaviour are less likely to get the help they need than those who do not present problems. Grant & Moores (1977) found that individuals with higher levels of maladaptive behaviour were less likely to receive “warm and developmentally promoting contacts” from staff. Felce et al (1987), replicating Warren & Mondy (1971) in adult services, found that contact from staff was rare and maladaptive behaviour was not discouraged. Challenging behaviour is also a risk factor for abuse (Rusch, Hall, & Griffin, 1986; Turk & Brown, 1993). In a study including some people with challenging behaviour, Felce, Thomas, de Kock, Saxby and Repp (1985) showed that the physical environment of institutions was relatively restricted and barren. Oliver, Murphy & Corbett (1987) reported that people with challenging behaviour were less likely than others to get access to day care in institutions. Often, people with challenging behaviour in institutions are likely to be congregated together on special wards or units, which may present problems of client throughput, staff turnover and quality of care (Hoefkens & Allen, 1990; Newman & Emerson, 1991; Raynes, 1980).

How best to serve people with problem behaviour therefore represents a continuing challenge to community services at the present time. Despite the development of many effective interventions for problems at individual level and an emerging technology of positive behavioural support (LaVigna & Donellan, 1986), deploying this technology in services is apparently often problematic. In this situation it is relevant to provide demonstration projects which attempt to integrate positive behavioural support with life arrangements which offer high quality experiences in all domains of the person’s experience (Bellamy, Newton, LeBaron, & Horner, 1986; Risley, 1996).

This chapter reports the results of such a project, designed to provide residential services in the community for people with severe and profound intellectual disabilities
who had such serious challenging behaviour that they were said to need continuing institutional placement. There have been few reports of such projects. Horner et al (1996) provide one example, and earlier work in Oregon (Newton, Romer, Bellamy, Horner, & Boles, 1988) and in Britain (Felce, 1996) included people with challenging behaviour in innovative community-based residential programmes. The chapter provides a comprehensive account of the project. It describes the people served and the services set up to replace institutional care; it presents the results of evaluation studies which tracked changes after transfer and compared different service models; it examines individual cases to illustrate success and failure; and it reflects on the achievements, problems and implications of the project for services to this client group and for future research.

A The project

The project took place in south-east England, as part of a large programme to replace hospitals for people with intellectual disabilities (Korman & Glennerster, 1990), led by a regional health authority (a strategic planning body responsible for the National Health Service for 3.7 million people in Kent, Sussex and South-East London). Initially, it had been planned to build new, smaller hospitals, including several special units for people whose challenging behaviour was regarded as the most difficult to manage (South East Thames Regional Health Authority, 1979). By the early nineteen-eighties the emphasis had shifted to the development of community-based services following the ‘Ordinary Life’ model (King’s Fund Centre, 1980; Mansell, 1988; Mansell, 1989; Mansell, Felce, Jenkins, de Kock, & Toogood, 1987) and the plans for special units were questioned as out of date.

An alternative proposal (Mansell, 1984; Mansell, 1985) called for the creation of a ‘Special Development Team’ to enable local services to develop the expertise to maintain individuals with serious challenging behaviour in the community. This proposal was endorsed in 1985 (South East Thames Regional Health Authority, 1985) for people with severe and profound intellectual disabilities. A different model, based on a short-term treatment unit, was adopted for people with mild intellectual disabilities (Clare & Murphy, 1993; Dockrell, Gaskell, Rehman, & Normand, 1993; Dockrell, Gaskell, Normand, & Rehman, 1995; Gaskell, Dockrell, & Rehman, 1995; Murphy, Holland, Fowler, & Reep, 1991; Murphy & Clare, 1991; Murphy, Estien, & Clare, 1996).

The Special Development Team (SDT) was created in 1985. The Team’s remit was to help local agencies develop individualised placements for people with severe and profound intellectual disabilities who had the most serious challenging behaviour (Emerson et al., 1987). The strategy of setting up the Special Development Team was intended to fulfil several distinct purposes:

♦ it was intended to help local agencies meet the needs of their most difficult-to-serve service users, at a time when they faced many other pressures due to the pace of the hospital closure programme

♦ it was also hoped that these local projects would serve as demonstration projects through which local services would have the opportunity to develop policies,
procedures and competencies which would be applicable to other services for people with severe intellectual disabilities within their own area.

- the strategy also had the implicit objective of helping to demonstrate to local and national policy makers that well planned community services provided the best option for all people with severe intellectual disabilities, including those presenting the most seriously disturbed behaviour.

It was not required that each person’s challenging behaviour be successfully treated or resolved before they moved to community settings, not least because one of the reasons for replacing the hospitals was their failure to meet such complex and highly individualised needs. Nor was it believed that challenging behaviour would necessarily disappear after transfer to the community, since there is evidence from other projects (eg Lowe, De Paiva, & Felce, 1993), and good reasons to predict (McGill, Emerson, & Mansell, 1994), that this will not happen. It was intended to manage and treat challenging behaviour as far as was possible, given the constraints of lack of knowledge as well as practical considerations. It was believed that better resourced and better organised placements in the community ought to help make this possible. But the primary goal was to enable the individuals concerned to experience a good quality of life in spite of any continuing challenging behaviour.

B The context

Research and development projects like the Special Development Team depend not only on the characteristics of the initiative but on the arrangements which provide the context in which the project takes place. There are two distinctive features of the English context which are relevant.

First, English government policy, though favouring the development of community-based services, has remained equivocal about the future role of institutions for people with multiple disabilities or with challenging behaviour (Department of Health, 1989b; Department of Health and Social Security, 1971; Department of Health and Social Security, 1984). Despite the development of model services which did serve these people, first in larger community-based facilities (Felce, Kushlick, & Mansell, 1980) and then in staffed houses (Felce, de Kock, & Repp, 1986a; Felce & Repp, 1992; Mansell, Jenkins, Felce, & de Kock, 1984), government policy continues to hold open the option of institutional care (Emerson et al., 2000).

Second, English services have a poorly developed infrastructure of professional resources required to deliver skilled intervention of the kind required by people with challenging behaviour. The great majority of residential care staff are untrained and staff with relevant qualifications are scarce (Department of Health and Social Security, 1979). There are weak management incentives to achieve quality outcomes for individuals (Mansell, 1996). There is a national shortage of clinical psychologists in the specialty (Management Advisory Service to the National Health Service, 1989) and only a tiny proportion of people with challenging behaviour have psychological treatment programmes (Oliver et al., 1987).

Thus the feasibility of small-scale community-based residential services for people with intellectual disabilities and serious challenging behaviour was in question both in
national policy and in terms of the readiness and capability of local service agencies. Participation by these agencies in the project was voluntary. The Regional Health Authority funded the Special Development Team, expressed its policy commitment to the Team and its work and offered financial incentives to local services to work with the Team. But some local agencies did initially opt to make alternative provision (such as institutional care in new hospitals, or out of area placement in private or voluntary homes).

II PROVIDING HIGH QUALITY SERVICES IN THE COMMUNITY

This section describes the characteristics of the people served, the characteristics of their placements and what happened to them. Information about placement quality mainly comes from an evaluation study which followed 18 of the original referrals made to the Team over a 4½ year period and included 13 of the 22 clients for whom placements were actually established (Mansell, 1994; Mansell, 1995).

A Service users

The Special Development Team used a highly individualised approach to assessment and construction of an effective service package. The process had four stages, involving case identification (Emerson et al., 1988), the development of an individual service plan (Toogood et al., 1988), support in commissioning services (Cummings et al., 1989) and, finally, providing additional support to new placements during their initial years of operation (Emerson et al., 1989; McCool et al., 1989).

Figure 1 shows the number of referrals made to the Special Development Team and their progress during the life of the project. Although many people with severe or profound intellectual disabilities may present behaviour problems (Qureshi, 1994), those served by the Special Development Team were chosen because they had the most extreme and durable challenging behaviour. The project had been conceptualised initially as focusing on the ‘most challenging’ individuals with severe or profound intellectual disabilities living in two large institutions scheduled for replacement by community residential services; these individuals were recognised to present exceptional challenges to services and had originally been destined for new institutional placements.

Figure 1 Progress of referrals to Special Development Team

The 35 individuals accepted onto the Team’s caseload had the following characteristics:

♦ 25 were men and 10 were women, their overall average age being 26 years (range 13 to 39)

♦ Most had spent much of their lives in institutional settings, an average of 16 years (range 0 to 33). Only three individuals had never lived in an institutional setting, these being three of the four youngest individuals (all in their teens) who had lived (apart from respite and other temporary breaks) all their lives with their families
Many had lived in several different placements, not counting different wards within institutions. The average number of previous placements was three with a range of 0 (those living with their families) to 11.

29 clearly presented severe or profound intellectual disabilities. Six individuals had a lesser or unclear degree of intellectual disability. They were, nevertheless, accepted as referrals because the level of everyday support they required was similar to the rest of the group and for the pragmatic reason that no other specialist resource was willing or able to support service development.

All displayed more than one seriously challenging behaviour and many displayed several. The most frequently occurring behaviours were aggression, destructiveness and self injury. Typically, problems included scratching, punching, kicking, biting, throwing objects (chairs, tables, crockery) at people and hand-to-head self-hitting. For many people, these behaviours were relatively infrequent in the institutional setting (happening several times each week but not every day), possibly because these settings provided very low levels of demand. They were sufficiently serious that the individuals concerned were identified as the most difficult to serve in the institutions. This level of difficulty was reflected in the prescription of psychotropic medication (hypnotics, sedatives, anti-psychotics and anti-depressants) for purposes of behaviour control; all bar two (two of the youngest people) were receiving such medication.

In all but one case, service users’ challenging behaviour had a long history and was reported to have emerged early in life. Challenging behaviour was reported before the age of six in 13 cases and before the age of 11 in a further 16 cases. Lack of information about some individuals is likely to mean that problems first emerged rather earlier than reported.

Challenging behaviour had, in a number of cases, proved resistant to treatment at specialist units. 23 individuals had attended such units at some time of their lives, in some cases more than one unit on more than one occasion. In particular, 12 of the group lived at the time of referral in special wards or units operated by the Regional Health Authority’s long stay hospitals for people with the most difficult problems and five were similarly resident in specialist resources outside the Region. Eight individuals had (as children) attended a specialist NHS unit in London for the treatment of children with severe behaviour problems.

In 16 cases analogue assessment procedures (Iwata, Dorsey, Slifer, Bauman, & Richman, 1982) were (or had been) used to assess the function of service users’ challenging behaviours. For all but one individual (where the results were unclear) these procedures suggested clear relationships between aspects of the person’s behaviour and environmental arrangements. The most common relationship involved the occurrence of challenging behaviour to escape demands but evidence was also found of some behaviours being motivated by access to attention, stimulation or tangible outcomes (Emerson et al., 1988).

23 individuals were reported to have significant impairments in addition to their intellectual disability and challenging behaviour. In particular 10 individuals were
reported to have epilepsy, six sensory (especially visual) impairments, five autism and five physical limitations as, for example, associated with cerebral palsy and leading to mild/moderate mobility restrictions.

Qualitative descriptions of two of the service users may serve to emphasise the severity of the problems presented. An assessment report based on one person’s institutional placement before resettlement included the following:

“... these (behaviours) include assault of others (pulling hair, pinching, scratching), manual evacuation and smearing of faeces, removing and tearing her clothes, eating inappropriate objects (eg, torn clothing), throwing objects and stealing food. These behaviours occur on at least a daily basis if she has the opportunity. Aggression occurs regularly and persistently whenever she is approached. She currently spends the majority of her day sitting or lying under a blanket in the corner of the ward. The combination of faecal smearing and aggression on others approaching has led to her being avoided by staff unless it is absolutely necessary to approach her ... in general she is a very challenging young woman who will respond with unpleasant aggression (faeces smeared hand in the victim’s hair) if approached.”

Similarly, a second individual was described as follows:

“General behaviour could be described as hyperkinetic. He will sit or lay for lengthy periods of time, continually rocking. He will run rather than walk ... He expresses very violently aggressive behaviour towards staff and residents. These disturbed periods ... generally begin with him becoming withdrawn and sullen with frequent incidences of faecal smearing and manual evacuation. He will then become very uncooperative and aggressive ... with no apparent provocation.. he will suddenly run toward a fellow resident or member of staff and launch into a full physical onslaught ... he will claw at the eyes and facial area of the person he is attacking. He will also bite, although his teeth are removed ... He is separated from the person he is attacking and conveyed to his seclusion with minimum force.”

The case identification process resulted, therefore, in a named group of service users who presented substantial and long-lasting challenging behaviours which had proven difficult either to treat or manage successfully.

B Individual planning

In total, 31 individual service plans were developed for clients in 14 District Health Authorities (service funding and providing organisations each serving about 250,000 people). The plans involved relatively high levels of service and were therefore expensive. Typically, a process of negotiation about the plans ensued with the authority in which program considerations were traded-off against costs. Of the 31 plans prepared, 25 were accepted by the responsible authority and led to the establishment of 22 placements.
In general, the placements were set up to reflect best practice in using ordinary housing to support people in the community, following the ‘Ordinary Life’ model (King’s Fund Centre, 1980). In most areas in which the Team worked, the placements were similar to other services being set up locally for people moving out of hospital. They were houses or flats for the individual concerned, usually living with one or a few others, supported by a team of staff (ie they were small staffed houses or group homes). In the remainder of this chapter these settings have been called specialised staffed houses in order to differentiate them from other residential provision in the community.

In addition, special emphasis was paid to adopting what has come to be called an ‘active support’ model of care (Jones et al., 1996; Mansell, 1998; Mansell et al., 1994a), which required staff to be particularly well-organised in the support they offered service users and had major implications for staff training and for first-line management. This approach, described by McGill and Toogood (1994), was developed from that described by Mansell et al (1987; 1984) and Felce (1988), and presented in a series of video-assisted training materials (Brown & Bailey, 1987a; Brown & Bailey, 1987b; Brown, Bell, & Brown, 1988; Brown & Brown, 1988; Brown & Brown, 1989; Brown, Ferns, & Brown, 1990; Brown, Toogood, & Brown, 1987). In general, ‘active support’ has four components:

- **service users are offered opportunities to take part in everyday activities at home and in the community, rather than childish or special therapeutic activities. The advantages of using real activities are (i) there is much more variety, (ii) many service users find them more interesting, (iii) they are less dependent on staff to signal each step and (iv) they provide opportunities for service users to show that they can take part successfully in ordinary activities like other people (Felce, de Kock, Mansell, & Jenkins, 1984; Mansell, Felce, de Kock, & Jenkins, 1982)**

- **staff pay particular attention to working as a team and to scheduling and co-ordinating the choices and opportunities they offer. This involves establishing routines (like those found in everyone’s lives) for the carrying out of ordinary activities (Saunders & Spradlin, 1991) and regular (on a shift or daily basis) planning of how they will systematically share themselves across clients to provide the high level of support needed, often by more than one person at a time, for meaningful participation**

- **staff focus on helping service users take part minute-by-minute (‘every moment has potential’), finding the parts of complicated tasks that even the most disabled person can do and doing the other parts of the task themselves, so that the person is almost guaranteed to succeed. Staff provide graded levels of assistance to ensure success and take account of individual preferences for activities and types of help to reduce the likelihood of challenging behaviour**

- **staff carefully monitor, using simple record-keeping procedures, the degree to which service users are taking part in ordinary activities with the right level and kind of support. Regular, client-centred staff meetings allow for plans to be**
modified in the light of experience and support consistent practices across the staff group.

While the primary purpose of this approach was not to teach skills nor reduce challenging behaviours it provided a context within which these desirable outcomes became more possible. Incidental opportunities could be taken as they arose with individual programmes reflecting current best practice being developed where useful or necessary. The best chance of success for these programmes comes when they are part of a rich, varied life, so that the task is to attend to the quality of the whole of the person’s life, and not to make them wait while their behaviour is ‘fixed’ or until they become more independent.

The Team provided additional professional support to the placements during the first 1-2 years of their operation (and in some cases for longer). The aim was to gradually reduce Team support as the local agency gained in experience and confidence. This approach was intended to reduce the often encountered problems of failure to transfer innovation from the supervised to unsupervised situation (Anderson, 1987). At all times the new placement was managed by the local agency and therefore fitted in with local management arrangements.

C Placements

Of the 22 placements established 13 have been maintained to date, seven in the original community setting, six in new community settings resulting from planned relocations (within the same district). As of February 2000, these 13 services had been maintained for periods of between 8 years 5 months and 12 years 5 months, an average of 10 years one month. Nine had closed for a variety of reasons:

♦ In two cases (2 clients sharing a house) lead agency responsibility changed hands from the District Health Authority (DHA) to a not-for-profit organisation funded jointly by the DHA and the Local Authority. In the face of operational and financial difficulties this organisation subsequently relocated the individuals to a local service for six people, most of whom presented some degree of challenging behaviour.

♦ In three cases the project closed because the lead agency (two different DHAs) felt that the client’s behaviour could not continue to be managed within a community-based setting. In one case the client was moved to a ‘crisis intervention’ placement on the periphery of a large hospital where he remained for 11 years, before moving to a 6-person unit for people with challenging behaviour in another part of England. In one case the client was relocated within the District to a small intellectual disability hospital and, subsequently, to a private psychiatric hospital where he remained for 8 years, before moving to a 10-person unit for people with challenging behaviour. In the third case the client was relocated to a private psychiatric hospital and subsequently to a private placement but, with support from the Special Development Team, returned to a newly developed placement in her home district which remains in place nine years later.

♦ In one case the client died of a heart attack nine months after the placement was established; in a second case the client died as a result of status epilepticus nine
months after the placement was established; in a third case the client was moved, eventually to a nursing home, because of physical deterioration, where he subsequently died; in a fourth case the person died in an accident.

D Service user groupings

The average number of clients per placement (including the SDT client) was 2.9 with three people living with no handicapped co-tenants, six with one other, six with two others, four with three others and three with four others. In general, then, the placements established were for slightly smaller groups of people than was common in residential care for people with intellectual disabilities (Raynes, Wright, Shiell, & Pettipher, 1994). While numbers of co-tenants were similar to those planned, there was a significant difference in their characteristics. Many co-tenants displayed challenging behaviour (18 out of 42) and this was sometimes of a serious nature. Indeed eight clients had co-tenants who were themselves SDT clients. This contrasted sharply with the original plans in which it was envisaged that only four co-tenants would display challenging behaviour, three of whom would be SDT clients (see discussion of rationale on page 19). Similarly, the original plans usually described co-tenants as being more competent than SDT clients. As 33 out of 42 also had severe intellectual disabilities this aspiration also seems to have been generally not met.

E Buildings

At the beginning of the project, most service users lived in two large institutions for people with intellectual disabilities in south-east England. One had been built in 1886, with barrack-block wards and detached villas built later, the other had been built between the wars and consisted entirely of detached villas. Both hospitals were destined for closure, the older closing in 1989 and the other in 1992.

These settings were of very poor quality. Participants lived either in ordinary hospital wards or in wards or units designated for the care of people with behaviour management problems. The ordinary wards provided most space (average 629 m$^2$) but also had the most residents (average 19). The special units provided on average 409 m$^2$ and had on average nine people resident. In the hospital wards about 15% of the space was unavailable to residents, compared to 36% in the special units. Among others, the rooms restricted included, in almost all cases, the kitchen, bedrooms, bathrooms, staff office and rest rooms, cleaners’ cupboards, laundry and other storerooms. Half the group lived in wards which were kept locked. The material environment was typically dilapidated, barren and somewhat bizarre. There were sometimes shortages of furniture, and in other cases there were unusual arrangements (eg one ward had 17 sideboards and wall units in the living room).

The houses and flats provided in the community were quite different. They were usually ordinary properties among houses owned by the general public, but in three cases they were on the same site as other residential facilities. They were usually bought on the open market. While many properties required substantial modifications these were dictated more by the needs of the property than by the needs of the service user. Modifications made to take account of the challenging behaviours presented by
service users included strengthened glass, soundproofing and electrical circuit breakers, but these modifications were made selectively in response to individual need rather than routinely. Although providing less space than the institutions (average floor area 92 m²), the houses provided as much space per person (average three residents) and all the space was available to the residents. The material environment was much richer than the institutions, with the full range of typical furnishings and equipment. Furniture, fixtures and fittings were selected to be as aesthetically pleasing as possible but also to minimise unnecessary risks and to withstand heavy prolonged use. These criteria sometimes resulted in more expensive, higher quality furniture being provided than customary in staffed housing.

F Staffing

In the institutional placements studied before transfer, staffing levels were relatively low (average 0.32 staff per resident in hospital, 0.64 in special units), although at least one person on duty was a qualified intellectual disability nurse. The houses had much higher staffing levels than the institutions (average 1.1 staff on duty per service user).

Staff teams had a home leader, and usually had one or more deputy/assistant home leaders, with the rest of the posts being support workers/care assistants. In some cases the recruitment and appointment policies of the provider agencies meant that senior placement staff had to have nursing qualifications. In others it was possible to appoint staff with other relevant qualifications or experience. Detailed job descriptions (Special Development Team, 1988) were developed to complement agencies’ existing materials. Recruitment (especially to home leader and deputy home leader positions) often proved difficult (Cummings et al., 1989) with few candidates having all of the desired attributes. Normal recruitment policies were used though it often proved necessary to advertise and/or to re-advertise nationally as well as locally. Even following this, it was in many cases necessary to appoint individuals with limited qualifications/experience and much to learn about working with people with challenging behaviour in community settings.

Some home leaders and deputy home leaders participated in an induction training programme provided by the SDT. This programme (Special Development Team, 1988) included coverage of the organising and setting up of services, the practical aspects of managing staff and resources in a small home, and approaches to managing and changing behaviour. In all services an induction programme of 1-2 weeks was provided for the whole staff group prior to the service opening. This programme was usually jointly planned and provided by the managing agency and the SDT and included coverage of the nature and causes of challenging behaviour, ways of recording behaviour, supporting service user participation in activity, assessment and teaching, as well as the more routine aspects of working in a small community-based home (Cummings et al., 1989).

G Costs

Detailed information about costs of each service is given in Emerson and McGill (1993) and McGill, Emerson and Mansell (1994). The average annual cost of the 22
established placements was £166,000 (range £77,600 to £271,400) at July 1999 prices. These are costs for the whole service, including all the residents, but not including the costs of advice and support from the Special Development Team. It is possible to make a crude adjustment to take account of these by costing the other places in each setting at the average cost of these types of service. Using data presented by Emerson et al (1999a), the average accommodation cost (including staff) for dispersed housing per place is £41,340 per annum. Reducing the placement costs by this amount for each person who was not a client of the Team would, in some cases, leave a cost for the SDT client of less than this. In these cases, it seems appropriate to divide the total cost equally among the residents. These adjustments yield an average cost per SDT client per annum of £101,500 (range £35,500 to £188,600). Thus, in general, these were very expensive placements when compared with ordinary staffed housing services.

However, specialised institutional placements for service users with serious challenging behaviour are more expensive than ordinary residential services. Dockrell et al (1993) provide cost information for a specialist unit for people with mild intellectual disability and serious challenging behaviour, and for private institutions. Adjusting the data to July 1999 prices gives an annual cost per place of £105,200 in the specialist unit and £74,000 in the private institution. Data from one District Health Authority (A Powell, East Kent Health Authority, personal communication, 7 February 2000) at the time of writing gives average costs of £101,916 per place for 12 people in specialist units (range £63,277-£156,950). Thus, the placements set up with the help of the Special Development Team have rather similar costs to the specialist units which end up caring for people whose local placements break down.

H Local professional and managerial support

The importance of support from local professional and managerial staff was recognised at the outset, both because the community placements were trying to meet relatively complex individual needs and because they were intended to function partly as local demonstration projects. Local managers and professionals (including senior staff not likely to be involved directly in the service) were involved in the planning process in an effort to generate local ownership and commitment.

Despite these efforts, placements often experienced insufficient local support. Home leaders often voiced concern about the lack of support from their middle managers and about the shortage of specialist skills, especially in the areas of behaviour management and communication. The lack of middle management support (for whatever reason - lack of commitment, time, or competition from other demands) resulted in many services in a failure to provide placement staff with clear expectations about what the placement should be achieving and how, a failure to monitor progress towards such achievements, and a failure to intervene at an early stage to resolve developing problems. Consequently, in some services, excessive autonomy was given to the home leader and staff group to determine working practices.

Local professional support was also very variable. While some services were able to make extensive use of clinical psychology, speech therapy, community nursing and
other such resources, these were much less available to others and completely absent in some.

III ACHIEVING A BETTER QUALITY OF LIFE

Quality of life was measured in the evaluation study by direct observation of how service users spent their time. Directly observing the experience of service users avoids inadvertently confounding measures of process and outcome; where evaluations have used measures of, for example, individual programme goals achieved it may be that the result owes more to staff activity (in this case, in setting achievable goals) than to real differences in service user experience (de Kock, Saxby, Felce, Thomas, & Jenkins, 1985; Repp & Barton, 1980). User activity patterns have been widely studied in research on British intellectual disability services (Emerson & Hatton, 1994; Emerson et al., 1999b; Felce, de Kock, & Repp, 1986b; Felce et al., 1980; Joyce, 1988; Mansell et al., 1984; Rawlings, 1985) and are beginning to be used in routine service monitoring (Hewson, 1991; Hewson & Walker, 1992). There is, therefore, a good basis for comparison of results with other studies.

Although activity patterns themselves do not provide much information about such qualitative goals as the choice open to an individual, or the respect in which they are held, it is likely that improvements in these areas will be reflected in the variety of activities and the extent of the person’s participation in them; and that if low levels of engagement in meaningful activity are found this reflects a genuine problem whatever other measures may indicate (Mansell et al., 1987). Although some attempts have been made to use interview schedules (O’Neill, Brown, Gordon, Schonhorn, & Greer, 1981) direct observation currently provides the most accurate way of measuring the activity of users (Joyce, Mansell, & Gray, 1989) who are unable to speak authoritatively for themselves.

In all, data was collected on nine occasions between February 1987 and September 1991, although not all participants were included at each occasion. At each datapoint, observations were collected for 11 hours from 08:00 to 19:00, typically built up in three shifts on three days in the same week. Days were primarily selected to fit in with observers’ work schedules, but where observers or staff believed that observation on a particular day would produce untypical results (eg where a participant was unwell or where a special event was planned) observations were rescheduled where possible.

The participants in the evaluation study were the first people in the long-stay hospitals for whom individual service plans were developed. Although it is not possible to be sure that they are representative of all the people served by the Special Development Team (since the Team did not collect standardised information on all its clients) they were a very disabled group (Figure 2).

Figure 2 Characteristics of participants of evaluation study

The primary measure was a 20-second momentary time-sample, collected using a hand-held computer (initially Epson HX20s, then Psion Organisers). Details of the
procedures and definitions are given in Beasley, Hewson, & Mansell (1989). A 20-second interval was selected as sufficiently accurate to examine data averaged over periods as short as an hour (Mansell, 1985; Repp, Barton, & Brulle, 1982).

Observers followed the participant as unobtrusively as possible throughout the observation period. Observations were not made where the participant or staff indicated that they wished them to stop, nor in intimate or private situations, nor when (in a few cases in institutions) the person was in seclusion. Observers were also instructed to cease observing and intervene if needed to protect the participant or other people from harm and this was occasionally necessary. Of the maximum possible number of observations (just over 212,000) 6% were missed for these reasons.

At each observation, the observer recorded the participant’s behaviour in four categories: activity, social behaviour, contact from other people and problem behaviour. At least one code was entered in each category and multiple codes could be entered if necessary.

♦ Activity codes comprised no activity (eg doing nothing, just walking about, sitting), leisure (eg playing an instrument, watching television, completing a jigsaw), personal (self-care activities eg eating, washing), using equipment (eg operating a food blender, a hedge trimmer, a vacuum cleaner), other practical tasks or chores (eg sweeping up, laying table, folding laundry), work or formal education (eg participating in a teaching programme), out walking (eg walking in the park, walking to shops). A code was also entered if the participant was in seclusion.

♦ Social codes were no social behaviour, clear social act (eg speaking to someone, tugging their sleeve), unclear social act (eg vocalising and waving arms near a person) and social act to observer.

♦ Contact codes (contact by other people to the participant) were no contact, positive (eg praise, hug) negative (eg hitting, restraining), neutral (eg conversation, passing the time of day) and assistance (directly helping the person do a constructive act, eg holding a bowl while they used an electric whisk, guiding their hand while cutting, pointing or telling the next step in a chain of tasks). Contact from other clients was distinguished from contact from staff or visitors.

♦ Problem behaviour codes were no problem behaviour, self-stimulation (eg hand-weaving, stereotypical body movements), self-injury (eg head-banging, wrist-biting), aggression to others (eg hitting, spitting, kicking), damage to property (eg smashing furniture, tearing clothes), inappropriate vocalisation (eg moaning, screaming, swearing) and then additional codes for other problems defined specially for each individual (eg faecal smearing, absconding).

Reactivity was assessed using the code ‘social act to observer’. Negligible levels of social contact from participants to observers were recorded. Twelve of the thirteen participants were recorded as contacting observers for less than 1% of observations. One person (participant SS) was recorded as contacting the observer for between
0.1% and 2.25% of observations (average 0.54%, equivalent to 3.5 minutes in the 11-hour day observed).

Before each datapoint, observers retrained on the measure by jointly rating videotapes until they reached a criterion of at least 80% agreement (including occurrence and non-occurrence). At every datapoint, inter-observer agreement was assessed for each participant by having a second observer independently collect data for 30 minutes (on a few occasions these reliability sessions were missed due to practical difficulties). This yielded 7615 paired observations (3.6% of the total). During the study point-by-point agreement, weighted by occurrence and non-occurrence, was calculated at each datapoint and ranged between 84 and 95%. Point-by-point agreement and Cohen’s kappa (Kazdin, 1982) were calculated for each code using all the available data and these statistics are reported for each of the results given below.

Figure 3 shows, for each of the 13 participants in the evaluation study, the overall level of participation in meaningful activity and the level of major and minor problem behaviour at each observation before and after transfer to homes in the community.

Figure 3 Participation and problem behaviour before and after transfer

A Participation in meaningful activity

Meaningful activity included any leisure, personal or practical activity, using equipment, work or education, or interaction with someone else (clear or unclear social with any contact), and excluded no activity, just walking, or in seclusion. The measure is therefore closely comparable with ‘engagement’, as defined in other studies. Inter-observer agreement (R) for this variable was 92% and kappa (k) was 0.70.

In the institutions, there was usually absolutely nothing to do except sit, walk about or watch television. A few participants, on a few occasions, attended therapy or day care sessions but generally they were excluded from these because of their behaviour. Participants had average levels of participation in meaningful activity of 14% (range 4-26%). This was largely made up of leisure (average 4%, range 0-12%; R=99%; k=0.78), personal (average 6%, range 3-9%; R=97%; k=0.71) and practical activity (average 3%, range 0-8%; R=97%; k=0.63). Using equipment (R=100%; k=0.77) was observed at a negligible level and work/education was not observed at all.

All participants showed an increase in the overall level of participation in meaningful activity after transfer to staffed houses. On transfer, individuals increased their level of participation by between a third and over six times their average baseline level. Taking the immediate pre- and post-transfer data, this was a statistically significant increase (t=-4.61, df=12, p=0.0005 (one-tailed test)). The consistency of the improvement across staggered transfer times strengthens the belief that this was a result of the move to staffed houses, rather than to the passage of time or general improvement in services.

Increased participation (average 36%) was made up of more leisure (average 7%, range 0-29%; immediate pre- and post-transfer means not significantly different, t=-0.60, df=12, p=0.279 (one-tailed test)); more personal (average 11%, range 5-24%; t=-4.91,
df=12, p<0.001 (one-tailed test)), more using equipment (average 2%, range 0-8%; t=-3.86, df=12, p=0.001 (one-tailed test)) and more practical activity (average 10%, range 1-38%; t=-4.16, df=12, p=0.0005 (one-tailed test)). Work/education was very rarely observed, and never for more than 1% of the time. This reflects in part that only one person in the specialised staffed houses attended day programs. This was primarily due to lack of funding, lack of programs (other than traditional Social Education/Adult Training Centres which were considered inappropriate) and unclear agency responsibility for these service users.

All but one member of this group, where there is sufficient data to judge, showed relatively good maintenance of participation levels over time (the exception is PH, though the level is still well above baseline). Those individuals transferred back to institutions show corresponding declines in participation, as does one of the people (HM) transferred to another staffed house to save money.

What this means for an individual is shown by the example in Figure 4. This presents a picture of the pattern of activity for one person (WG) on the last day observed in institutional care and the first day observed in her new home in the community. In the institution, WG did almost nothing for most of the day (she was engaged in meaningful activity for 77 minutes out of the 10 hour 10 minutes observed). The three peaks of activity represent breakfast, lunch and tea, when she ate her meals.

In her new home in the community, there was a substantial increase in WG’s level of participation. WG was engaged in meaningful activity for just under four hours in the 11 hour 20 minute day observed. The main increase in engagement in meaningful activity was in everyday household tasks (cooking, cleaning, laundry, shopping) - real tasks relevant to WG’s life in the community.

B Staff contact

Figure 4 also shows the staff contact received by WG before and after transfer. For people with severe or profound intellectual disabilities, staff contact is especially important. This is because staff provide the help and encouragement that people need to take part in everyday activities. In particular, previous research has suggested that it is the amount of direct practical help which is important, rather than general conversation. In the institution, WG received contact from staff at a low level throughout the day (in total amounting to 67 minutes) but most of this was in the form of general conversation - constructive help occurred for only 11 minutes. After moving to the community, she received much higher levels of contact from staff and a much higher proportion of contact was in the form of assistance. Total contact was received for five hours ten minutes, of which just under half (2 hours 28 minutes) was in the form of direct, practical assistance.

Figure 5 gives a picture of the relationship between staff contact and service user engagement averaged across the three kinds of environment - hospital wards, special units and community houses - involved in the evaluation study. Contact was categorised as assistance ($R=89\%; k=0.25$), other contact, consisting of positive, negative
or neutral contact \((R=94\%, 99\%, 95\%; k=0.03, 0.32, 0.52)\) and none \((R=91\%, k=0.65)\). The low kappa values reflect the low occurrence reliability of these codes; occurrence was however low, making the data still useful. Most (84-90\%) other contact was neutral - typically conversation, like passing the time of day. Negligible amounts of contact were received from other clients.

Figure 5 Participation and staff contact in institution wards, units and houses

The hospital wards and special units showed similar, low levels of contact to the study participants (raising the question of what is ‘special’ about special units). For over 90\% of the 11-hour day observed, people did not receive any contact from staff. This is comparable with other studies of hospitals (eg Rawlings, 1985).

Staff in the houses provided significantly more other contact \((t=5.74, df=12, p<0.0001\) (one-tailed test)) and assistance \((t=4.06, df=12, p=0.001\) (one-tailed test)) on transfer from the hospital environments. However, even in the houses, people only received contact for a quarter of the time. This is similar to the levels reported in two staffed houses (29\% and 20\%) from the Andover demonstration project by Felce et al (1986b), but given the high staffing ratios might be thought capable of improvement. While, in general, studies suggest higher levels of contact in staffed houses (Emerson & Hatton, 1996) outcomes have been very variable. Some studies (eg Hughes & Mansell, 1990) have shown levels of contact (in three houses for other service users with intellectual disabilities provided by one of the agencies with whom the SDT worked) as low as in hospital (7, 9 and 10\%), despite much higher staffing levels. This suggests that the problem of low levels of contact may have persisted in ordinary community services, in which case the levels achieved by the specialised staffed houses studied here may be more creditable.

Figure 5 also shows that the increased engagement by people when they moved to houses was not solely due to assisted performance; unassisted engagement also increased significantly \((t=-3.78, df=12, p=0.0015\) (one-tailed test)). Unassisted engagement was quite strongly correlated both with assistance \((r=0.2596, p<0.005)\) and neutral contact \((r=0.4301, p<0.0001)\). Compared with the Andover demonstration project (Felce et al., 1986b), houses in this study, though showing similar levels of staff contact provided rather less of it in the form of assistance (9\% compared with 25\% and 14\% in the two houses Felce studied).

These average results conceal considerable variation between individuals and over time. In the hospital wards and special units, the average total contact received by individuals in each condition ranged from 1.6\% to 12.7\% of observations. After transfer, total contact ranged from 13.2\% to 45.5\%. The level of contact received by individuals was not significantly related to their level of adaptive behaviour, further reinforcing the importance of staff management variables.

Contact in the institutional settings was relatively stable over time, with the exception of MT, whose level of contact increased from two to 20\% just before transfer. With this exception, however, the hospital wards and special units provided relatively constant (low) levels of contact. In the houses there was much greater variability,
indicating how enriched settings provide the potential for change, without necessarily ensuring it.

C Social interaction

Taking the whole group across all observations, average social interaction (where the study participant was interacting or attempting to interact and they were receiving contact from another person) was only 2% (range 0-17%; $R=97\%$, $k=0.41$). Only in one case did there appear to be a change associated with transfer: SS increased social interaction from an average in baseline of 2% (range 0-4%) to 12% on transfer to a specialised staffed house, and this declined to 5% on return to institution.

Most people received negligible contact (i.e., less than 0.5 per cent) from other service users ($R=100\%$, $k=0.71$). MT, MM and MS were recorded as being contacted by other service users for 1% (approximately seven minutes) in the 11 hour day on only one of the data-points; one person (BF) received this level of contact on two data-points; and one other (FP) received 26 minutes in 11 hours on one data-point. This reflects the degree of handicap of the people served and suggests that, for this group at least, any suggestion that large (or small) residential facilities currently provide important social relationships with other people with intellectual disabilities is mistaken.

D Challenging behaviour

Challenging behaviour was separated into minor and major categories. Minor problem behaviour was made up of stereotyped behaviours, which usually occurred for a large part of the time. Inter-observer agreement ($R$) for minor problem behaviours was 91% and kappa ($k$) was 0.73. Major problem behaviours were self-injury, aggression to people, damage to property and other idiosyncratic problems. Inter-observer agreement ($R$) for major problem behaviours averaged 97% (range 90 to 100%) and kappa ($k$) averaged 0.40 (range 0.01 to 0.92). Low kappa values reflect poor occurrence reliability for some of the least frequent behaviours.

Although the average level of minor problem behaviour was lower after transfer (falling from 29% to 16%) there was much variability within and between individuals, and some individuals had increasing or reducing minor problem behaviour before transfer (see Figure 3). The change immediately before and after transfer is not statistically significant ($t=1.45$, $df=12$, $p=0.085$ (one-tailed test)). Two people showed clear increase after transfer (HM, PH); two people (MS, MT) showed an increase throughout the study; two people (JK, MM) showed no change; four people (BF, GF, SM, FP) showed a decline throughout the study which was maintained after transfer; and three people (SS, WG, ST) showed a clear reduction after transfer.

Eleven of the 13 participants show negative correlations between scores at each datapoint for participation in meaningful activity and self-stimulatory behaviour of between $r=-0.0189$ and $r=-0.9914$, although only in two cases (ST and WG) is this statistically significant ($p<0.01$).
Despite their reputation, the individuals in this study only showed major problem behaviours in sporadic outbursts during observation. The data for major problem behaviour should, therefore, be interpreted with caution because the selection of days for observation may not have included enough days to accurately sample major problem behaviour. It is also the case that the observational measure used did not differentiate more from less intense outbursts.

There is similar variability in the major problem behaviour data. The average level fell after transfer (from 9% to 4%) but the change between immediate pre- and post-transfer scores is not significant ($t=1.27, df=12, p=0.114$ (one-tailed test)). Two people (MS, SM) showed clear increases after transfer; two people (HM, SS) showed no change; three people (BF, GF, PH) showed a reduction during baseline which continued after transfer, and one person (WG) showed a reduction in baseline continued after transfer but increasing on readmission to institution and again on return to a staffed house; five people showed a reduction on transfer (ST, JK, MM, MT, FP).

Taken together these findings suggest that seven of the 13 people were better off, or no worse, after transfer in both categories of problem behaviour; three had more minor problem behaviour, two had more major problem behaviour and one person increased in both categories.

Figure 6 shows the amount of staff contact observed in the three kinds of setting and its disposition in relation to major problem behaviour. In each setting, major problem behaviour occurred for only a small proportion of observations. In the hospitals and special units, it occurred with about 13% of the contact observed; in the houses 8% of the contact occurred with major problem behaviour. It is perhaps not surprising that most of the major problem behaviour occurred when there was no staff contact, since this may reflect the opportunity to behave in this way and the avoidance of the person by staff during bouts of dangerous behaviour. In the houses, the provision of assistance solely when major problem behaviour was not observed probably reflects the care given in setting up these placements to manage the level of demand placed upon the individual concerned, since this was often an important trigger for disturbed behaviour.

Figure 6 Problem behaviour and staff contact in institution wards, units and houses

E Skills

Increased engagement in meaningful activity means that people are living fuller, richer lives in spite of the severity of their intellectual disability and the continued presence of behaviour problems. One would expect that increased engagement would lead to an increase in skills, and this is indeed what seems to have happened. Where possible, Part One of the Adaptive Behavior Scale (Nihira, Foster, Shellhaas, & Leland, 1974), which had been used to describe the abilities of people participating in the evaluation study, was repeated at the end of the study. Figure 7 shows the gains and losses made by the 11 individuals concerned (one had died, and one was terminally ill).

Figure 7 Skills of evaluation participants at follow-up
Seven of the eight people in the study group who were still in specialised staffed houses showed substantial net gains in their score on the Adaptive Behavior Scale (maximum score 279), ranging from 21 (MS) to 58 (WG) points (average 40). GF, who was the highest scoring individual at the beginning of the study, showed a substantial net drop in score (-28 points). The three people who had been transferred to other environments (SK back to a local hospital, HM and ST to a larger staffed house) showed changes of +15, three and -15.

**F Effects on co-tenants**

Special Development Team services were characterised by attempts to avoid congregating people with challenging behaviour, even though this was not always achieved. Critics of this strategy point to its potential negative impact of living with a person with serious challenging behaviour on co-tenants. While no information on this aspect of user outcomes was collected as part of the formal evaluation study, some informal observations may be made as a result of information collected from internal monitoring systems.

In general, the possible picture of co-tenants living a vulnerable, frightened existence was not found. There were very few reports of co-tenants being attacked or otherwise threatened. Undoubtedly, there have been times when they were living in a fairly disturbed and disturbing environment. However, their sometimes higher levels of ability, or prior planning, often allowed them to escape from such situations to conditions of greater privacy within or outside the house. More positively, there was also anecdotal evidence to suggest that co-tenants benefited from the higher staffing levels, structured programming, and external professional involvement associated with the projects. This is, however, based on very limited information. The effects of challenging behaviour on other residents should be a priority for further research.

Such concerns are rarely raised regarding services which congregate people with seriously challenging behaviours together in one setting. If people with intellectual disabilities have the right not to live with others who show challenging behaviour then this right must be extended to all people with intellectual disabilities including people with challenging behaviours themselves. Thus, the ethical issue is one of whether it is appropriate for anyone to live and work in close proximity to someone with seriously challenging behaviours. Congregating together people with challenging behaviour does not provide a solution to this problem. Service providers have, of course, a duty of care to ensure that all those receiving services are protected from harm. This duty draws attention to the importance of giving careful consideration to the risks presented to others by an individual’s behaviour. This applies whether the ‘others’ display challenging behaviour themselves or not.

**IV INDIVIDUAL ILLUSTRATIONS OF PLACEMENT SUCCESS AND FAILURE**

The overall evaluation of staffed houses set up with the help of the Special Development Team showed a substantial improvement over the institutions they
replaced. But within this picture there was important variation between individuals. This was examined in a study by McGill and Mansell (1995). The three cases presented in this section have been chosen because they illustrate particular issues. The first is a service which has experienced considerable success and which has built on its strengths. The second is a placement which was closed to save money, the individual concerned being transferred to a larger staffed house in which most residents had challenging behaviour. The third is a failed placement, from which the person was readmitted to institutional care, followed by successful re-establishment of residence in the community.

A “Sue Thompson”

Sue Thompson (not her real name; SM in the evaluation study) lived with her family until she was six. She had profound intellectual disabilities, and developed destructive behaviour which presented her family with major problems. In 1960, Sue was admitted to a large intellectual disability hospital, where she spent the next 28 years of her life. In 1980 the first author, visiting the hospital, was shown Sue as an example of the kind of person that it would not be possible to care for in community services: at that time, she spent most of her day sitting in the middle of the ward day room, naked, in a puddle of her own urine, under a blanket. She was said to resist aggressively any attempt to change this arrangement. Her challenging behaviours included stereotyped behaviour (twiddling string, jumping up and down on the spot, tooth grinding), aggression (biting, pulling hair, scratching), damage to property (ripping sheets and clothes, throwing cups and plates), stripping, non-compliance, handling, eating and smearing faeces and insisting on remaining under a table and/or a blanket.

The initial assessment records of the SDT show that there was no psychological behaviour management programme at the start of the project. Sue’s challenging behaviour was not even recorded unless it was exceptionally serious. Behaviour management was attempted through medication: Sue was prescribed chloral hydrate (sedative), thioridazine (anti-psychotic) and tetrabenazene (anti-parkinsonian).

Sue’s reputation, and an initial dispute over agency responsibility, caused delays in the plans for her resettlement. As a result, when the hospital closed, Sue spent time in three interim placements while her community service was developed. The last and longest of these was a special unit for people with challenging behaviour on the periphery of another large intellectual disability hospital. In 1990, she moved into her new community service. This was a four-bedroom detached house in a residential area which she shared with three other people who had mild or moderate intellectual disabilities and who did not have serious challenging behaviour.

Data collected in the evaluation study (Figure 8) show Sue’s lifestyle and behaviour across three different settings: two datapoints five months apart in her original hospital, one a year later in the special unit on the hospital campus and two a year and two years later in the specialised staffed house. In hospital, Sue received very little contact from staff (an average of 3.5%, or about 25 minutes in an 11-hour day). In the special unit the total contact increased to 6% (about 45 minutes). Only in the specialised staffed house did contact markedly increase, to an average of 46%. A
significant proportion of this staff contact consisted of assistance to Sue to participate in meaningful activities. While such assistance occurred for just over 1% and 2% respectively of the time in the two institutional settings, it averaged 25% in her community placement.

Figure 8 “Sue Thompson”: behaviour and contact in three settings

Given the severity of her disabilities, there is little doubt that this increasing level of assistance was responsible for Sue’s increasing participation in meaningful activity (such as housework, leisure activities, socialising and so on) from 3% and 7% in her previous settings to an average of 20% in the staffed house.

There was a dramatic decrease in the percentage of the day Sue showed challenging behaviour on transfer from hospital to the special unit. This overall result was, however, mainly due to a very marked reduction in sitting under a blanket. After moving to the staffed house, Sue’s challenging behaviour increased from 15% in the special unit to an average of 23% in the staffed house, there being small but important increases in aggressive and non-compliant behaviour. These increases probably reflect higher levels of social contact and of ‘demand’ in the staffed house. The evidence of the second observation point in the staffed house suggests that these increases may have stabilised while contact, assistance and participation continue to increase. The character of Sue’s aggression is also much less unpleasant. While she still grabs staff and pulls their hair, attention to her toileting and physical needs has led to her no longer wearing incontinence pads and to her using the toilet appropriately, with help. As a result, faecal smearing now happens very rarely.

What was responsible for obtaining these marked differences in Sue’s behaviour over three years? The simplistic suggestion that it was due to moving to a house is not supported because the special unit was actually located in a house on the periphery of the hospital and was set up to function as independently as possible from the main hospital campus. It was as close to other domestic (albeit rural) houses as it was to the main hospital, had its own entrance and it was furnished much more like an ordinary home than the hospital’s wards. Nor was the change due to increased use of medication. Sue’s psychotropic medication reduced after transfer; she was still prescribed thioridazine and orphenadrine, but chloral hydrate and droperidol were replaced by diazepam.

Nor can these results simply be explained by the staff ratio of the different services. The hospital wards had many service users looked after by a few staff, but the special unit had a 1:1 ratio of staff allocated to service users. This was in fact slightly higher than the ratio in the staffed house. The ratios observed (rather than allocated) were rather different: in the hospital at the first observation point the average numbers of staff and service users observed in the same room with Sue were 2.6 and 9.8 respectively (a ratio of 1:3.8); at the second observation point, Sue spent 69% of the time on her own and without staff present. Although the special unit had much higher staff ratios, the observed ratio was 1:3.6, similar to the first observation in hospital, and Sue was in a room on her own and without staff for 59% of the time. In the staffed house staff were virtually always present and the observed ratio was 1:1.
The difference in observed staff ratio between the special unit and the staffed house may partly reflect the service user groupings in these services. In the special unit, Sue lived with three other people all of whom had major challenging behaviours. An associated study (Emerson, Beasley, Offord, & Mansell, 1992) of the special unit showed that disproportionate amounts of contact went to those other residents who displayed higher rates of challenging behaviour. In the staffed house Sue’s three co-residents did not present similar levels of challenging behaviour and did not require as much help from staff.

It is also likely that the differences in observed ratios and in results reflect differences in the model of care in these three settings. In the hospital, especially in its closing months, the model of care was overwhelmingly custodial - staff were simply engaged in a holding operation. Low levels of interaction by staff with service users were the norm and individualised planning procedures were rudimentary and ineffective. Sue’s ‘timetable’ in the hospital (Figure 9, based on information collected when she was first referred to the Team) shows that there were virtually no activities planned for her.

Figure 9 “Sue Thompson”: weekly hospital timetable

In the special unit, the model of care was focused more on treatment, since one of the unit’s central aims was to reduce service users’ challenging behaviour. With Sue, the special unit was partly successful in doing so but without being able to replace that behaviour with anything more meaningful. The treatment emphasis also may explain the very low rates of contact between staff and Sue (given the high staff ratio) - treatment in a medical setting is traditionally administered in short bursts. For example, one of the unit’s approaches to Sue was to offer her an opportunity to participate in an activity every half an hour. Most activities, however, were very brief so that in between these opportunities Sue would be largely left to her own devices.

In the community service the model of care was described as ‘active support’ (see above) - the organisation of the environment and the provision of assistance to increase individual participation in an ordinary lifestyle. This involved giving attention to what the individual person would be doing throughout the day (not just at particular moments), the kind and amount of support they would need to do it (including which staff will be doing what, when and with whom) and the collection of evidence about what happened - in what activities, for example, did the person participate throughout the day. Figure 10 shows a small portion of the planning for a typical day.

Figure 10 “Sue Thompson”: part of daily plan in community

Without this planning and structure people with severe or profound intellectual disabilities will not be able to do very much and, when they display challenging behaviour, there will be nothing to which staff can redirect them (one of the primary staff tasks is “waiting” for challenging behaviour to occur). In the early days of her community placement a deliberately ‘relaxed’ regime was adopted because placement staff felt, despite advice from the Team, that this was needed. However, this approach was associated with difficulties in managing Sue’s behaviour. As structure (a balanced day’s activities, clear guidelines for staff on how to work with Sue, advance planning,
recording of participation and behaviour) were added in, Sue’s behaviour became more manageable and her participation in meaningful activity increased.

B “Howard Monk”

The second example, Howard (not his real name; HM in the main study), had also lived in an intellectual disability hospital for over 20 years, since 1967 when he was nine years old. Like Sue, he had a profound intellectual disability. Howard presented a wide range of challenging behaviours mainly involving damage to property, including rummaging in garbage bins, overturning furniture, breaking windows, sweeping objects off shelves or tables and breaking property or objects. He had also hit, kicked and head-butted people. He had several stereotyped behaviours, made inappropriate noises and masturbated in public. Howard also had no psychological treatment for his challenging behaviour at the outset of this project. He was prescribed medication for behaviour management purposes (thioridazine).

Planning of Howard’s new service proceeded fairly smoothly against a background of increasing pressure on the local service agency to resettle its “own” residents from the soon-to-close hospital. The service was developing new homes for over 60 people and, while fairly well resourced professionally, was finding its management capability stretched. In a compromise to the preferred plan (to save money) Howard was found a three-bedroom house to share with one other man (also an SDT client) who presented similar levels of challenging behaviour and was as heavily disabled as Howard. This staffed house opened in mid-1988.

The service agency was able to appoint relatively experienced senior staff with a strong commitment to community living. From the outset, however, problems arose. Despite the local and external professional support that was available, the placement’s senior staff preferred to take their own counsel. As a result, there was considerable conflict between placement staff and professional workers. The latter believed that the placement was taking too laissez-faire an approach and they were particularly concerned about the placement’s rejection of well-established approaches to the management of challenging behaviour. Placement staff rejected the advice offered as too behavioural and prescriptive, opting instead for methods similar to ‘gentle teaching’ and a strong emphasis on respecting service user choice. Attempts to resolve these conflicts were initially unsuccessful, as the agency’s senior managers were not able to provide placement staff with clear expectations or monitor their achievement. Data from the Team’s records show that after an initial improvement in important areas of placement activity a steady decline set in (Figure 11).

Figure 11 “Howard Monk”: placement performance over time

Although it eventually proved possible to establish better working relationships, staff turnover in this period was high – most staff had left by the end of the first year and most of their replacements had left after another six months. Incidents of challenging behaviour became more serious as the service relied more on new or temporary staff. Management arrangements changed to reflect national community care policy developments and the managers of the new agency felt that the existing placement was too expensive, especially given its relatively poor performance. Howard (and the other
man) were consequently moved to a larger, though still local, setting designed to congregate service users with challenging behaviour.

The results obtained from the evaluation study are shown in Figure 12. In the hospital, Howard’s level of participation in meaningful activity increased and his level of challenging behaviour decreased over observation points. Most of the activity was leisure (typically the simple manipulation of pre-school toys such as an ‘activity centre’ or teddy bear) and most of the challenging behaviour was stereotypy. Levels of contact from staff were very low, with negligible levels of assistance. On transfer to the staffed house the overall level of contact increased markedly but most of this was neutral rather than assistance. This reflected the staff practice of asking Howard whether he wanted to do something and taking no clear response to mean he was choosing not to take part, repeating the request a few minutes later. Howard’s level of participation in meaningful activity fell slightly and challenging behaviour (again mainly stereotypy) more than doubled. At the following observation point participation increased and stereotyped behaviour fell, but the observer reported that the participation was very simple manipulation of a guitar prompted by staff, which the observer felt might have been intended to affect the results of the study. After transfer to the large staffed house for people all of whom have challenging behaviour, Howard’s level of participation was halved (nearly as low as at the beginning of the study) and challenging behaviour had also fallen markedly.

Figure 12 “Howard Monk”: behaviour and contact in three settings

Several lessons can be drawn from this experience. First, although the staffed house was part of a larger organisational system, the staff had great autonomy: as the Special Development Team reported to the agency at the end of their involvement

> “the changes in the service management structure meant that there was little or no real management time accorded to this placement. Therefore the team leader and deputy were ‘left to get on with it’ as best they could. In the absence of formal management and organisational guidance they took on the responsibility for deciding the direction of the placement”.

While autonomy is generally thought to be a quality-prompting characteristic of services (cf King, Raynes, & Tizard, 1971), it should not mean creating a vacuum of management or leadership, lest staff practices drift away from the goals of the service (Mansell, McGill, & Emerson, 1994b). Staffed houses for people with challenging behaviour probably need a greater share of management time and leadership. Without such support, community houses will depend too much on the quality of house staff, who, in any case, may well move on relatively quickly.

Second, Howard’s experience illustrates the importance of correctly interpreting prevailing philosophy and matching the values and goals enshrined in it with a practical technology for achieving them. The observers’ interpretation of the results in the staffed house was that staff had understood the principle of normalisation as meaning primarily that Howard must be offered choices to do valued activities. In practice, this was operationalised as making complex verbal requests, even though Howard had almost no receptive or expressive language, and de- emphasising ordinary
household activities as sources of possible service user involvement. The net result was that staff spent a lot of time asking and cajoling him, but since Howard usually did not respond or became disturbed, staff eventually did much of the available activity themselves. This is a misunderstanding of the principle of normalisation; choice is only one of a number of important outcomes which exist in tension with each other (O’Brien, 1987). It is also a misunderstanding of the nature of choice; as Mansell et al (1987, p.200) point out:

“Choice’ is a loosely used term in this context: better to distinguish between different conditions of choosing. We say that someone chooses to do one activity rather than another when they can do both (they have the skills, resources and time and they control access to each option)…For people who have difficulty expressing their preferences, whose range of experience is limited, and whose ability to control their environment is severely impaired, failure to create opportunities for participation is just as ‘controlling’ as setting up only one option. It ensures that people can only do nothing. The goal should therefore be to find ways of enabling people to express their preferences, to ensure that they routinely experience a wide range of different circumstances and to arrange their environment so they can control it. Only as these conditions are fulfilled can one say that people are in some sense making informed choices”

Finally, this example shows that the survival of relatively expensive and sophisticated services for people with very special needs partly depends on political understanding and commitment. It is largely the responsibility of the service to protect itself from threat by making sure that the reasons for high costs are understood, providing ‘good news’ about the placement and, by good management, avoiding ‘bad news’ such as complaints from the public. Despite local concern among consumer groups about the removal of Howard from his home to a larger staffed house to save money, the poor results achieved effectively neutralised this source of local support and advocacy.

C “Wendy Green”

The third example, Wendy Green (not her real name; WG in the main study) was born in 1955 and admitted to long-term hospital care in 1961. Wendy also had profound intellectual disabilities. Like Sue and Howard, Wendy had a wide range of serious challenging behaviours including stereotypy, wrist and hand-biting, aggression, faecal smearing, tearing clothing, loud screaming, stripping, vaginal digging and pica. In hospital, Wendy typically spent up to a quarter of her day roaming unsupervised around the hospital grounds, in all weathers. Typically, she would try to gain entry to ward kitchens where she would gulp tea or coffee (of whatever temperature) until stopped. Some staff treated this as a major problem and would eject her from their ward; other tolerated her visits and Wendy was a well-known ‘character’ in the hospital. There is no record of psychological treatment for Wendy’s behaviour problems, which were treated with pericyazine.

When the hospital closed, Wendy moved to her own apartment in a house in which one of the other flats was also occupied by people with intellectual disabilities - the staff team being shared between the two flats. At first, this service was very successful.
In the first twelve weeks of its operation, Wendy’s participation in household and community activities showed a steady increase (Figure 13) and data collected for the evaluation study a month after her move (Figure 14) showed that Wendy was receiving over four times more contact from staff than when in hospital, including 11 times more assistance. Her participation in meaningful activity had tripled, and challenging behaviour was at a third of its previous level (mainly reductions in stereotyped behaviour, pica and stripping).

Figure 13 “Wendy Green”: placement performance over time

Figure 14 “Wendy Green”: behaviour and contact in three settings

However, as staff turnover began Wendy’s behaviour began to deteriorate. After a year the Special Development Team reported

“...the absence of a house leader {for four months} has meant that all the ...training input during the first year of the service has been effectively lost...there are now none of the original support workers in post who may have been relied upon to maintain consistent service delivery...the extensive use of agency staff is necessary simply to maintain staffing levels...recruitment is a permanent feature of management time”.

Wendy became very noisy and many complaints were made by neighbours. Following psychiatric assessment she was moved to a private psychiatric hospital and then to a private residential home. Figure 3 shows that her level of participation was lower than in the staffed house, but not as low as in hospital, and there was a very small increase in challenging behaviour. Staff contact declined markedly.

As part of a wider project with the whole service agency (Mansell et al., 1994a), designed to address problems of placement breakdown and the lack of capacity in the system to serve people with challenging behaviour, a new staffed house placement was set up for Wendy and she moved back in 1991. With a new staff team trained in the model of care, the pattern of staff contact returned to that of her first placement and participation increased to over 40% of the day.

Wendy’s case illustrates the importance of the wider service system when setting up specialised staffed houses for people with highly individual needs. A specialised staffed house is a complex arrangement of individual components which make up the intervention package; from details of individual ways of working with the individual (ways of communicating, kinds of help the person needs, individual programmes) to policies, staffing patterns and resources. Where a person has serious challenging behaviour the risk of tinkering with these carefully planned arrangements is greater. Where the service agency does not really recognise this and does not practise caution in its dealing with other staffed houses, it is not likely to either recognise or understand the importance of decay in the specialised setting. It may, therefore, not notice or care if posts are held vacant to save money, if staff practices cease and if monitoring becomes ineffective. The agency is also less likely in these circumstances to value the skills and knowledge of staff in the specialised staffed house and to use
them elsewhere in the service; and it will not have the skills and knowledge in other staffed houses to help out in times of crisis. When the specialised staffed house faces particular problems it may therefore be already weakened and the agency may not have the capacity to support it: the placement breaks down.

Specialised services for people with challenging behaviour therefore need to be embedded in service systems which are capable of sustaining them, in which the gap between specialised practice and that in the main stream of intellectual disability services is not too great.

V SUMMARY AND CONCLUSIONS

A Main findings

Although such a small, very disabled group may not be representative of people with serious problem behaviour elsewhere, the individuals served in the Special Development Team project were selected by local service agencies as presenting the greatest challenge to resettlement. Since the project covered a mixed rural and urban area of approximately 3.7 million total population, the results are likely to be broadly applicable to other areas. The results of this very detailed, long-term study do therefore make a significant contribution to the policy question of the relevance of different treatment approaches as hospitals are replaced by alternative services.

The results show that it has been possible to set up community-based placements which offer much richer social and material environments than the hospitals they replace. Given the extreme nature of the problems experienced by this client group and the long history of failure by services to do more than provide custodial care, this is a significant achievement. Where placement breakdowns have occurred this appears to have been due to failure to keep all the elements of the individual package of care in place.

In terms of their participation in meaningful activity, the individuals included in the evaluation study experienced significant improvement on transfer from institutions to staffed houses in the community. Despite some evidence of decay, participation has remained higher than in institutions. Increased participation has, in general, been matched by growth in the competence of individuals.

For most people in the evaluation study, improved participation was achieved without increase in the kind of major problem behaviour which had led to their exclusion from ‘mainstream’ intellectual disability services in the first instance. The new services had not set out with the expectation that they would necessarily reduce problem behaviour (though they had of course used their best efforts), because of the intractability of some of the problems and the difficulty of sustaining sufficiently skilled staff performance given local conditions and shortages of professional specialists. To have helped many people improve their participation in community-based settings without worsening of their challenging behaviour or placement breakdown is therefore a very positive outcome.
The results of the Special Development Team project should therefore give encouragement to decision-makers to select well-organised placements in the community, rather than institutions, for people with severe and profound intellectual disabilities and challenging behaviour. The evidence of this project suggests that even specialist institutional provision, including hospital-based housing, provides a very poor quality of life for clients, despite the resources which have been invested in it. One way of summarising the changes observed in this project is in terms of added value: on average the houses had just over double (2.2 times) the staff:client ratio of the hospitals and special units; but they delivered 3.4 times the staff contact and 4.5 times the assistance to the individuals served. They were therefore able to use the greater resources they had more efficiently, and this had greater effectiveness in terms of client participation in meaningful activity without overall increases in problem behaviour.

The results of this study are consistent with recent American research on similarly organised services (Horner et al., 1996). In the present policy context in England, the implication is that proponents of institutionalisation as the first choice option for people with severe or profound intellectual disability and serious problem behaviour now need to produce evidence that these services can achieve comparable outcomes. The results of this study have shaped new Government guidance (Department of Health, 1993) which identifies the improvement of community services to meet the needs of people with problem behaviour as a major goal and accepts the use of institutions only as a stop-gap while this is being achieved.

However, this project also illustrates just how difficult it can be to implement new approaches in service delivery. The problems encountered provide important information about the context in which specialised community-based services are developed and the tasks facing decision-makers and innovators. The remainder of this section discusses these problems in four clusters, concerning poor performance of residential services, the relationship between specialist and generic services, pressures due to the deinstitutionalisation process and pressures due to cost reduction programmes.

B Poor performance of residential services

The good results achieved in this project depended on highly individualised planning and on placements which used an ‘active support’ model of care. This involved the careful planning of activities, the structured deployment of staff, the implementation of agreed and detailed plans for the promotion of activity and the management of challenging behaviour, and the keeping of careful records about the success of the strategies being used. However, within the services set up with the help of the Special Development Team, there was considerable room for improvement in the extent to which this model of care was put into practice.

Poor performance was most commonly manifested in two ways: clients continuing to display unmanaged and poorly understood challenging behaviour which was potentially dangerous to themselves, others or their environment; and clients, whether or not they were displaying challenging behaviour, spending very little of their time in meaningful activity. In the former situation there was, aside from the risks to everyone involved, considerable danger of the placement breaking down. In the latter, the client
might as well have still been in an institution for all the impact made by living in the community. In addressing these issues, the Team often found itself attending to the following:

♦ the development of procedures that enabled staff to organise themselves to support client participation in meaningful, preferred activities. Staff often had great difficulty thinking of what they might be doing with clients and typically did not give enough attention to the organisational procedures necessary to ensure that things actually happened when they were supposed to happen. Individual planning and shift planning procedures were most useful here as ways of helping the staff team to develop a model of care focused on ‘active support’

♦ the training of staff in supporting clients to participate in activities which maximised engagement and minimised challenging behaviour. As the years progressed this training increasingly became ‘on-the-job’, owing to the difficulties of developing practical skills through classroom instruction and the great advantages of being able to model performance and give immediate feedback (Anderson, 1987)

♦ the encouragement of staff and their managers to engage in team-building and mutual support activities, which improved staff consistency and morale and helped to maintain a clear focus on the planned tackling of client issues over time. In particular the Team stressed the importance of regular client-focused meetings which involve the whole staff group and the availability of regular staff supervision to provide some of the emotional support undoubtedly required by people working in sometimes very difficult and frightening circumstances

♦ the development of clear written contracts (as well as more informal agreements) between the SDT and the referring agency as a means of clarifying the nature of the task involved in supporting such services. Such agreements emphasised the importance of the necessary local infrastructure (eg input from local professionals such as psychologists) and an active approach to managing the service which focused on the quality of the outcomes being achieved by and for clients.

None of these were instant solutions. They provided, however, ways of working with the placement which, deliberately, did not focus on the client as being the problem but rather attempted to support the development of a more competent service.

An American visitor to one of the SDT-supported services commented on how tolerant it was of challenging behaviour, saying that, in the services with which he was involved, there was much more intensive behavioural intervention to attempt to reduce challenging behaviour. This was an interesting comment, not least because SDT-supported services generally involved rather more of this kind of intervention than was or is common in British residential services. The Team’s approach was, however, influenced by its cultural context and focused rather more on the provision of a supportive environment than on the direct treatment of challenging behaviour. While, in some circumstances, such an environment, as a side effect, apparently helped to reduce challenging behaviour, this was not its primary goal. Rather the primary goal was to support people to be engaged in a more ordinary life. Most
services operated on the assumption that this could not wait until challenging behaviour had been significantly reduced as most of the clients had long-lasting, entrenched behaviours unlikely to be overcome very quickly.

In conditions of scarcity of staff, combined with difficult and stressful work, it is not surprising that high levels of staff turnover were also a problem contributing to poor performance in many services with which the Team worked (as is the case more generally - see Baumeister & Zaharia, 1987). This led to particular difficulties which services had in seeing client behaviour in a long-term context. This was manifested in a number of ways. The Team sometimes encountered the situation where a client had made great progress but this was not perceived by the service, even when many of the same staff were in post. Similarly staff were often unaware of progress made or problems occurring in previous settings and, without knowing it, were repeating work previously carried out (Di Terlizzi, 1994). This focus on the ‘now’ is also potentially problematic when, because staff forget or there has been significant turnover, no one is aware of why something is done in a particular way. For example, when a successful intervention is found which prevents challenging behaviour in a particular context the person may subsequently be seen as not having a problem in that context. The intervention is withdrawn as not being necessary without any awareness of its preventive value and the problem re-emerges. In some respects part of the SDT role was to act as the behavioural consciousness of the service, constantly reminding people of why things were done as they were and trying to encourage the taking of a longer-term historical perspective.

This perspective inevitably leads to a concern with the procedures used for ‘remembering’ the lives of people who cannot remember them for themselves. Since services cannot rely on the service user to tell them about the past and, partly because of staff turnover, cannot count on the memory of the staff, they need to provide a prosthetic memory through regular information collection. This information (e.g., about intervention programmes, challenging behaviours, problems and successes) needs to be available in a form which aids rapid identification of trends over time and which allows for the early detection of problems. Record keeping, while undoubtedly often a boring chore, may need to assume a new importance as a method of helping to achieve personal and cultural continuity.

C Relationship between specialist and generic services

Relationships between specialist and generic services for people with intellectual disabilities and challenging behaviour are often problematic because incentives exist for generic services to pass individuals on permanently (Newman & Emerson, 1991). In this project, attempts had been made to avoid this. Financial support was contingent on maintaining people locally; the specialised services were set up within the local territory and were part of the local service system. Nevertheless, there was wide variation in the degree and type of involvement of local managers.

In a few instances, the process of individual service planning was carried out by local professionals and service workers without sufficient involvement of senior decision-makers. When the plan was produced, key members of the agency were not properly prepared for its contents and costs and were not predisposed to react positively. In
some cases, initial contact by the local agency through making referrals was never translated into serious commitment to develop services, and time was wasted on plans which, in retrospect, never had much chance of implementation. Some plans probably involved too many compromises on significant issues; for example, the eventual placement groupings involved much more congregation of people with severe intellectual disabilities and challenging behaviour than had originally been envisaged, with consequent difficulties once placements were established. At the other extreme, some agencies saw the project as essentially about setting up services and tended to ignore the need for continuing support and monitoring, as in HM’s service described above.

The Team’s response to these problems developed, over time, in two directions. First, the Team itself was clearer about what it expected from local agencies wishing to collaborate and was less inclined to adopt speculative projects. It therefore used criteria relating to the ‘readiness’ and ‘capability’ of local agencies to focus its resources (Beckhard & Harris, 1987). Second, the Team made more use of contracts with local agencies to manage the process of setting up new services. This was almost entirely new in service development in Britain at the time, but presaged the widespread adoption of contracts after the 1989 community care reforms (Department of Health, 1989a). However, although detailed specification of mutual obligations and expectations helped make the relationship productive, it did not address the gap between the sophistication of the individual service plans and the reality found in ordinary services for people with intellectual disabilities. The overall context was of a shortage of skilled support staff and professionals.

Therefore the Team was trying to establish relatively sophisticated services against a background in which understanding of, and support for, what was being attempted was at best uncertain. The working methods (such as ‘active support’) which the Team wanted to introduce were new to staff and managers in local services. It was therefore difficult to recruit staff with experience of them. More than this, staff in other services and managers of the local agency were often unconvinced of the value of such an intensively organised approach, which they sometimes saw as in conflict with their interpretation of normalisation. Although staff in the specialised service could be trained, an indifferent or unsupportive local environment made it harder for them to sustain the approach required.

In circumstances such as these, where most community services are relatively unskilled, there is a trade-off between adopting greater control over the specialised services (in order to ensure better staffing, training, management and quality) and ensuring their integration in and ownership by the local service system. In this project, the consequence was that most placements were not as sophisticated, in terms of organisation of the staff support provided or of behavioural programming, as had been intended at the outset; but in most cases the placements were successfully integrated into the local service system.

### D Pressures due to the deinstitutionalisation process

It is important to bear in mind the context within which the Team worked. First, it was an initiative to support the closure of long-stay intellectual disability hospitals.
Closure of the hospitals was the overriding policy objective and its imminence lent a degree of urgency to the Team’s work which had both costs and benefits. Benefits included agency agreement to very innovative service plans which, in less urgent circumstances, may have aroused considerably more controversy. Costs included the need to give pragmatic considerations perhaps too high a priority in the planning and service development process. Second, it is easy to forget how new the SDT and its approach was at the time. The majority of professionals and policy makers believed that a significant minority of people with intellectual disabilities (including but not only the group with whom the Team worked) would need to remain in hospital or hospital-like arrangements. Most other areas of Britain were less advanced with hospital closure than South East Thames and there were no models (not even from other countries) of how to go about the Team’s task. Often, therefore, the SDT was quite literally making it up as it went along.

The definition of the task as deinstitutionalisation meant that the Team followed the pattern of previous service provision in concentrating on residential care, with the consequence that day service provision was relatively under-developed. Similarly, general health care was not given high priority, although there is evidence of extensive unmet need in institutional services (Kerr, Fraser, & Felce, 1996; Livingstone, 1996; Yeates, 1998).

The chronological development of services was such that a great many came ‘on stream’ within a short space of time, with several distinct consequences:

- The time at which many of the specialised services were established corresponded with the time during which local agencies were rapidly growing in size as they developed new services for the rest of their previously institutionalised populations. This meant not just stretched resources at the local level but more difficulties in maintaining the profile of Team-supported placements and good lines of communication with senior agency staff.

- There was considerable variation in the quantity of SDT involvement across different placements. Where local staff appeared to be able to get on with the job relatively competently they were inevitably left to do so more than in those placements where explicit demands were being made of the Team.

- There was also much variation in the nature of the support provided, which was probably largely dependent on the skills and experiences of individual team members. Thus, in some placements, the primary mode of support was direct work with and through placement staff. In other placements a rather more distant, organisational development role was adopted. At the time, this was justified in terms of variation in local conditions but it seems likely that it also served the interests of extremely stretched Team members in allowing them to exercise well-established skills confidently and autonomously.

The novelty of the Team’s approach, coupled with the pressure of time, also meant that, in retrospect, the Team’s methods were under-developed. Insufficient attention was given to the use of ‘clinical’ assessment strategies. While analogue assessment procedures (Iwata et al., 1982) were used in a number of cases the predominant mode
of enquiry was participant observation - a ‘getting to know you’ process (Brost, Johnson, Wagner, & Deprey, 1982) which resulted in useful qualitative but limited quantitative data. For example, the questions of whether users had vision or hearing impairments and their nature was left largely to a statement of existing perceptions of these problems. Given the known relatively high occurrences of these impairments in people with severe intellectual disabilities (perhaps especially in people who display challenging behaviour) (Department of Health, 1993) this was a significant omission. Relatedly, the information gathered to inform the planning process was insufficiently standardised so that relatively important information about, for example, the person’s placement history or the history of treatment approaches used with their challenging behaviour was only sometimes available.

E Pressures due to cost reduction programmes

The people served in this project were selected as having the most challenging needs and they probably represent the most expensive people to serve in any situation (unless simply abandoned to the neglect and abuse of very poor quality institutional care). The average cost per SDT client of the services established was £101,500 at July 1999 levels. These figures do not include the extra costs associated with managerial and professional support, day placement and so on.

In the mid to late 1980s it was possible to argue that such costs were justified almost as a question of moral right. Since the individuals catered for had often been deprived for most of their lives, since their needs were so great, it was entirely appropriate, went the argument, to now spend a lot of money on trying to provide something rather better. As the political context has become much more concerned with cost containment and accountability, this has become a less viable position. It is still possible to argue that services for people with such complex and demanding needs are expensive wherever they are provided (and in practice the costs of special institutional placements are often as high as these services), but there is no doubt that these kinds of community services are, at least sometimes, more expensive than ‘ordinary’ institutions.

It therefore became increasingly important to show that increased costs were justified by greater effectiveness. This had two implications for the Team’s work. First, it devoted considerable attention to both evaluating the performance of the services and to encouraging the development of internal evaluation procedures, which would make decisions about resources rather better informed. Second, the Team was forced to consider whether the resources actually allocated to the services were all now required. In general, all the services set up with the Team’s help faced pressures to reduce their costs over time. While there is sometimes scope for reducing costs, this cannot be done arbitrarily. The costs are high principally because of the number of staff required to be on duty at any one time to guarantee the safety of clients and staff with minimum recourse to restrictive methods of managing challenging behaviour such as seclusion. While the consequence of a 10% cut in staffing in an ordinary staffed house may be a reduction in out of house activities for clients, the consequence in a service for someone with significant challenging behaviour may be serious injury to the client, other clients, staff or members of the public.
Unfortunately such services are vulnerable not just to across-the-board cuts but, because they are often the most highly staffed and expensive services, to being asked to take a greater share of any cuts. Since cost containment is probably the most significant factor influencing the behaviour of senior managers, they are likely to prefer and reinforce models of supporting people which stress the non-professional nature of the 'caring' role and which do not seek to develop the technical skills of staff through potentially expensive training or the employment of staff with more advanced qualifications. Since managerial contracts and contracts for the provision of services are likely to be time-limited, short-termism is the implicit philosophy. Such a philosophy, of course, runs the risk of falling into the 'social trap' (Platt, 1973) of creating long-term negative outcomes for clients and others for the sake of short-term financial advantage. It is therefore very important, if these services are to survive, that there is understanding and commitment at the highest levels of the agencies concerned.

F Conclusion

The four clusters of problems described above are not, in themselves, primarily the result of the serious challenging behaviour presented by clients of the Special Development Team. They are problems of all residential services for people with intellectual disabilities. Indeed, the outcomes associated with these specialised services, when compared with the rather poorer outcomes typical of community-based residential services, suggest that these problems have been better handled here than elsewhere. Rather, challenging behaviour presents a particular test of how well services are organised and how skilled they are. Services that can respond constructively to challenging behaviour are likely to be able to achieve good outcomes for other service users.

This project also suggests how service responses to challenging behaviour might go beyond a limited concern with an individual’s behaviour, and its relationship to the immediate environment (the traditional concern of applied behaviour analysis), to a broader concern with the analysis and design of the service culture. In the terms used by Horner and O’Neill (1992), the task is to build “competent environments”. It is these environments, rather than just contingency management programmes, which represent the necessary “intervention”. They are consequently complex, multi-element interventions which need to be evaluated not just in terms of their effect on challenging behaviour but in terms of their effect on the broader lifestyle of clients. Horner and O’Neill suggest that competent environments will make challenging behaviour irrelevant (the consequences they obtain are there all the time anyway), inefficient (there are far easier ways of getting these consequences) and ineffective (they will not now obtain these consequences anyway).

Extending the focus of attention from the client to the placement would also not be enough. As research and development moves beyond the first generation of projects, set up under tightly controlled conditions, problems of management and the support of staffed houses become more important (Landesman, 1988; Mansell, 1996). There is a need to work at three levels: the relationship between the individual and their immediate environment, the relationship between how this environment is delivered
and how the home is organised; and the relationship between the home and the service system of which it is part (Mansell et al., 1994b).

This project still remains relatively unusual in Britain. Further research is needed to examine the possibilities of replication with people with a wider range of characteristics (including autistic spectrum disorders and mental illness in addition to their intellectual disability). In particular, further research needs to identify those characteristics of the organisation of staff and the residential setting which deliver therapeutic support to the individual person whatever their particular needs (Holburn, 1997). At an organisational level, research is needed which explains the breakdown of residential placements in terms of the lack of these organisational characteristics rather than simply the nature of the client’s needs.

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REFERENCES


Department of Health. (1989b) Needs and Responses: Services for adults with mental handicap who are mentally ill and who have behaviour problems or who offend. London: Department of Health.
Services for People with Severe Learning Difficulties and Challenging Behaviours: University of Kent at Canterbury.


Felce, D., de Kock, U., & Repp, A. (1986a) An eco-behavioral analysis of small community-based houses and traditional large hospitals for severely and
profoundly mentally handicapped adults. *Applied Research in Mental Retardation, 7*, 393-408.


Mansell, J. (1984) *The operation of regional special support services for people with mental handicap and behavioural problems*. Croydon: South East Thames Regional Health Authority.

Mansell, J. (1985) *Special services for people with severe mental handicap and severe behaviour problems*. Croydon: South East Thames Regional Health Authority.


South East Thames Regional Health Authority. (1979) *Strategies and Guidelines for the Development of Services for Mentally Handicapped People*: South East Thames Regional Health Authority.

South East Thames Regional Health Authority. (1985) *Mental Handicap Special Services*: South East Thames Regional Health Authority.


Figure 1 Progress of referrals to Special Development Team

- **95 referrals**
- **35 referrals accepted**

- **3 ISP started but no ISP agreed**
  - 6 ISP rejected or not responded to by District
    - 1 placement established after negotiation
      - 3 placements broke down
        - 4 clients died of natural causes
          - 1 placement maintained
          - 1 placement re-established
          - 10 placements maintained

- **29 ISP produced by SDT**
  - 23 ISP accepted by District
    - 19 placements established
      - 2 placements dis-established
        - 2 placements maintained

- **2 ISP produced by local staff with SDT advice**
  - 1 placement established

- **ISP not formally carried out for 1 referral**
  - 1 placement established

- **19 placements established**
- **23 ISP accepted by District**
- **2 ISP produced by local staff with SDT advice**
- **ISP not formally carried out for 1 referral**
- **1 placement established**

- **6 ISP rejected or not responded to by District**
  - 1 placement established after negotiation
    - 3 placements broke down
      - 4 clients died of natural causes
        - 1 placement maintained
        - 1 placement re-established
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- **29 ISP produced by SDT**
  - 23 ISP accepted by District
    - 19 placements established
      - 2 placements dis-established
        - 2 placements maintained

- **2 ISP produced by local staff with SDT advice**
  - 1 placement established

- **ISP not formally carried out for 1 referral**
  - 1 placement established
Figure 2 Characteristics of participants of evaluation study

<table>
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<th>Stim</th>
<th>SIB</th>
<th>Agg</th>
<th>Dam</th>
<th>Other problem behaviour and other conditions</th>
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<td>6</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>BF</td>
<td>F</td>
<td>1950</td>
<td>1964</td>
<td>211</td>
<td>4</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>strips</td>
</tr>
<tr>
<td>SS</td>
<td>M</td>
<td>1958</td>
<td>1965</td>
<td>86</td>
<td>4</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>WG</td>
<td>F</td>
<td>1955</td>
<td>1961</td>
<td>70</td>
<td>5</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>smears faeces, pica, strips; phenylketonuria</td>
</tr>
<tr>
<td>GF</td>
<td>M</td>
<td>1957</td>
<td>1975</td>
<td>78</td>
<td>5</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>pica, steals, absconds, inappropriate sexual behaviour; epilepsy</td>
</tr>
<tr>
<td>SM</td>
<td>F</td>
<td>1954</td>
<td>1960</td>
<td>49</td>
<td>4</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>non-compliance, strips, smears faeces</td>
</tr>
<tr>
<td>MT</td>
<td>F</td>
<td>1958</td>
<td>1968</td>
<td>110</td>
<td>5</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>smears faeces, strips; epilepsy</td>
</tr>
<tr>
<td>FP</td>
<td>M</td>
<td>1973</td>
<td>1990</td>
<td>94</td>
<td>3</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>non-compliance, vomits</td>
</tr>
</tbody>
</table>

Key:
ABS: Total score on Part One of AAMR Adaptive Behavior Scale
Stim: Number of different self-stimulatory behaviors
SIB: Self-injurious behavior
Agg: Aggression to other people
Dam: Damage to property
Figure 3 Engagement in meaningful activity and problem behaviour before and after transfer
Note:
A Institution
B Specialized group home
C Other group home
Figure 4 The pattern of WG's day before and after transfer

<table>
<thead>
<tr>
<th>Engagement</th>
<th>Assistance</th>
<th>Total contact</th>
</tr>
</thead>
<tbody>
<tr>
<td>8am to 7pm (approx)</td>
<td>8am to 7pm (approx)</td>
<td>8am to 7pm (approx)</td>
</tr>
</tbody>
</table>
Figure 5 Engagement in meaningful activity and staff contact in institution wards, special units, and staffed houses.

Institution ward
- Staff contact: 9 (No contact) 2 (Other contact) 2 (Assistance) 3 (Engaged) 84 (Disengaged)
- Client engagement: 88

Special unit
- Staff contact: 12 (No contact) 3 (Other contact) 2 (Assistance) 3 (Engaged) 80 (Disengaged)
- Client engagement: 85

Specialised staffed house
- Staff contact: 19 (No contact) 5 (Other contact) 9 (Assistance) 10 (Engaged) 57 (Disengaged)
- Client engagement: 69
Figure 6 Major problem behaviour and staff contact in institution wards, special units, and staffed houses
Figure 7 Changes in adaptive behavior after transfer

Change in ABS Part 1 Score

In specialised staffed houses at follow-up

Other settings

MT  GF  BF  WG  PH  MS  MM  SM  FP  HM  ST  SS
Figure 8 "Sue Thompson": behavior and contact in three settings
Figure 9 "Sue Thompson": weekly timetable before transfer

<table>
<thead>
<tr>
<th></th>
<th>Morning</th>
<th>Afternoon</th>
<th>Evening</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday</td>
<td>On ward</td>
<td>On ward</td>
<td>On ward</td>
</tr>
<tr>
<td>Tuesday</td>
<td>On ward</td>
<td>On ward</td>
<td>On ward</td>
</tr>
<tr>
<td>Wednesday</td>
<td>On ward</td>
<td>On ward</td>
<td>On ward</td>
</tr>
<tr>
<td>Thursday</td>
<td>On ward</td>
<td>On ward</td>
<td><em>Enjoys Top of the Pops</em></td>
</tr>
<tr>
<td>Friday</td>
<td>On ward</td>
<td>On ward</td>
<td>On ward</td>
</tr>
<tr>
<td>Saturday</td>
<td>On ward</td>
<td>On ward</td>
<td>On ward</td>
</tr>
<tr>
<td>Sunday</td>
<td>On ward</td>
<td>On ward</td>
<td>On ward</td>
</tr>
</tbody>
</table>
Figure 10 "Sue Thompson": part of daily plan after transfer

<table>
<thead>
<tr>
<th>Time</th>
<th>Task Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.00 am</td>
<td>Medication</td>
</tr>
<tr>
<td>8.30 am</td>
<td>TOILET Bath - Sue to wash herself, wash hair (hoh)</td>
</tr>
<tr>
<td>8.40 am</td>
<td>TOILET Dry self (sa)</td>
</tr>
<tr>
<td>9.00 am</td>
<td>TOILET Clean teeth, brush hair (hoh), apply perfume/ make up (hoh)</td>
</tr>
<tr>
<td>9.10 am</td>
<td>STAFF CHANGE Choose cereal and toast topping (sa), prepare and eat breakfast (ta)</td>
</tr>
<tr>
<td>9.30 am</td>
<td>TOILET Wash up (ta)</td>
</tr>
</tbody>
</table>

Key:

hoh = hand over hand assistance provided
sa = staff assistance provided
ta = pre-existing task analysis used
Figure 11 "Howard Monk": placement performance over time
Figure 12 "Howard Monk": behavior and contact in three settings

Percentage of day

Institution

Specialized staffed house

Other staffed house

Data Point

0 10 20 30 40 50 60

Total contact  Assistance  Engagement  Challenging behaviour
Figure 13 "Wendy Green": placement performance over time

Weekly total

No. household and community activities joined in
Figure 14 "Wendy Green": behaviour and contact in three settings

Percentage of day

Specialized staffed house

Other staffed house

Specialized staffed house

Total contact

Assistance

Engagement

Challenging behaviour