

## LOCAL SUPPORT UNITS FOR MENTALLY HANDICAPPED PEOPLE AND THEIR FAMILIES: AN EVALUATIVE STUDY

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*As a result of the development of care in the community the closure of many large institutions catering for mentally handicapped people is now imminent or accomplished. Consequently the development of an effective programme of locality based support is an urgent and major priority in many Health Districts. In Exeter an important innovation has been the setting up of Local Support Units (L.S.U.s) to provide a service for severely mentally handicapped people living in the community with their families or care-givers. In practice the move towards community care involves an increase in responsibility and burden predominantly on the families of mentally handicapped people (Byrne and Cunningham, 1985; Lockyer, 1985). An important aim of the units therefore was to provide a backup of accessible and effective support for families and other care-givers. In order to achieve this the units were highly staffed to provide an intensive range of support. This currently consists of facilities for short-term accommodation in cases of crisis or to provide respite, medical and psychological assessment together with some training in practical and social skills (Williams and Bratt, 1985).*

*It was recognised that each locality presented a different set of needs with varying facilities available at its disposal with which to meet them. For example a rural as opposed to urban area may pose specific problems such as isolation and lack of social facilities, for a young handicapped person and her family.*

*Also the profile of needs changes during a family's life-cycle (Black, 1982). A most significant and difficult period for many families is at the time of the leaving-home transition (Haley, 1980). In a family with a mentally handicapped person reaching adulthood there are many painful issues to face, especially in that the difficulties for the young person of living independently in the community outside of the family may now become painfully apparent. Other children who may have been involved in caring and helping may at the same time be attempting to leave home with the result that the parents can feel isolated and overwhelmed. An important consequence of this can be that the transition is delayed or postponed with some consequent negative implications for 'normalisation'. Instead of an age-appropriate disengagement from home the handicapped young adult may instead remain dependant at home. A consequence can be that rather than fostering a process of normalisation, (Wolfensberger, 1972), the mentally handicapped person may instead potentially suffer a form of institutionalisation as a result of a restriction to the family setting with consequent lack of social contacts and other stimulation (Slack et al., 1984; McConkey et al., 1981).*

*A further consequence of the delayed transition can be that problems may appear later in a more severe form to present intermittent crises and a painful transitional period when the parents become aged and their health deteriorates to the point that caring for their relative becomes too strenuous. There may be emotional and behavioural problems associated with increased dependence, together with medical problems since the client is older and more prone to illnesses.*

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At the same time their elderly relatives are also more likely to be frail and less able to deal with these difficulties at home.

In the face of this multiple and shifting set of demands the guiding model for the development of the units was an ecological one. In other words the units were seen as one interacting part of the overall range of facilities comprising the system of support in the community. Therefore the units were seen as needing to be adaptable and able to evolve to respond rapidly to the changing needs of, and resources for, clients and their care-givers in the local community.

### **AIMS AND HYPOTHESES**

The aim of the study was to examine the extent to which the units were meeting the needs, not only of the clients but also of their families or care-givers. A clear division between client and families needs was not made, rather the two were seen to be interdependent. For example families were found to be dissatisfied with the service if they perceived their relative as unhappy and likewise client's behaviour in the units and at home was found to be related to their family's condition. More broadly the intention was to provide information on the processes of care in the community and especially the interface between the families/care-givers and the units.

It was hoped that the information gathered could be usefully applied to the question of how the units should develop in the future. More generally it was intended that this study would be of relevance to attempts in other regions to implement community based support systems. The clients and their families were selected to cover a broad range of ages, economic circumstances education and type of disability. This is seen to be comparable to the range of users in other Regions though obviously such a small scale study has short-comings regarding generalisability. Furthermore it is possible that the Exeter area is unusual in that provision for families through the Honeylands scheme (Brimblecombe, 1974) and an effective community mental handicap team had already identified families who had a need for services of this kind and had ensured that most families with a need were aware of and had made use of the facilities at the units if necessary. However in other Regions it may be necessary to establish the extent of unmet need in the community as a prerequisite to the development of such units.

Specifically the aims of the study were to provide information on the following:

1. The profile of activities in which the units were currently engaged.
2. The extent to which the needs of the client-family system were being met.
3. An indication of gaps in the provision and requirements for a broadening of the service.

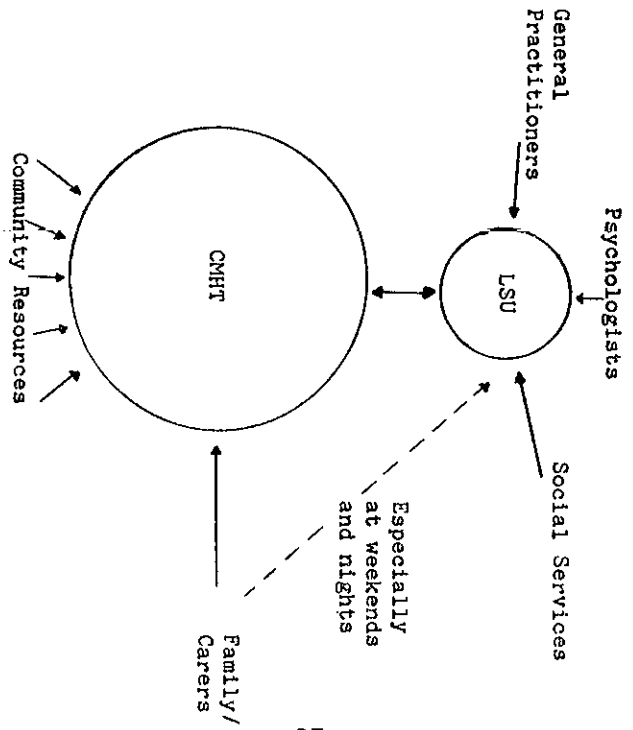
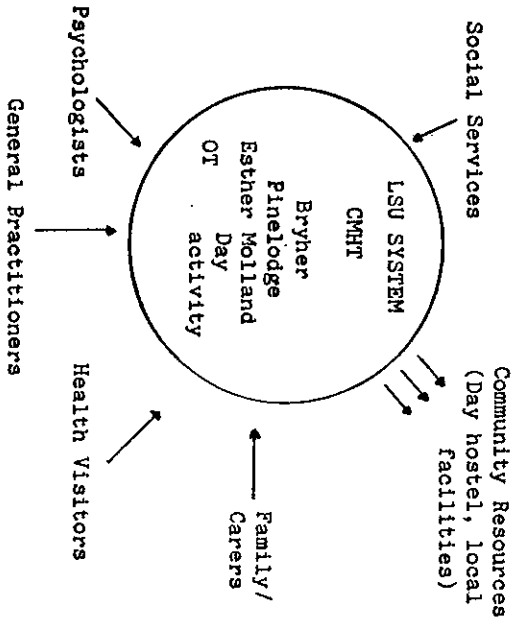
More generally it was hoped that the study would provide some indication of the effectiveness of the units and suggest some indications for future development. Some broad hypotheses drawn from the preliminary observations of the units, discussions with management and the literature, were as follows:

1. An ecological model of an evolving service based on continuing adaptation to meet local needs was appropriate.
2. The homely, non-institutionalised nature of the units would be liked by users.
3. That the issues of leaving-home and independence was a central one for mentally handicapped people and their families.
4. That the units would come to play an increasing part in the management of the problems associated with the leaving-home transition.

FIGURE 1. TWO MODELS OF L.S.U. ROLE: POSTHILL AND KNIGHTSHAYES

\*POSTHILL: GLOBAL CONCEPT

\*KNIGHTSHAYES: SPECIALIST CONCEPT



\* Knightshayes is located in an URBAN setting in the City of Exeter, whereas Posthill is in a RURAL setting 3 miles outside the town of Tiverton.

## METHOD

Two units, Knightshayes in Exeter and Posthill in Tiverton, were selected for the study. These were chosen because they demonstrated differences in their initial design and also significant differences in how they have evolved in keeping with local resources and geography (see Fig. 1).

Posthill, which is located in a rural setting outside Tiverton, caters for a dispersed population of users and has limited local resources. Consequently it represents a relatively self-contained 'global' concept, comparable to a small hospital complex. It consists of four separate buildings respectively providing day-care, for individuals having challenging behaviours, for individuals with severe physical disabilities, and a building housing the community mental handicap team. In contrast Knightshayes, located in the city of Exeter, is a single ten-bedded unit which offers a more 'specialist' service and is part of a wider profile of provision in Exeter which is orchestrated by the community mental handicap team located elsewhere in the city.

Though not totally distinct the two units embody two of the most common models of provision in the community. The intention was to utilise these differences in order to illustrate the units current and potential future use.

There were three parts to the study:

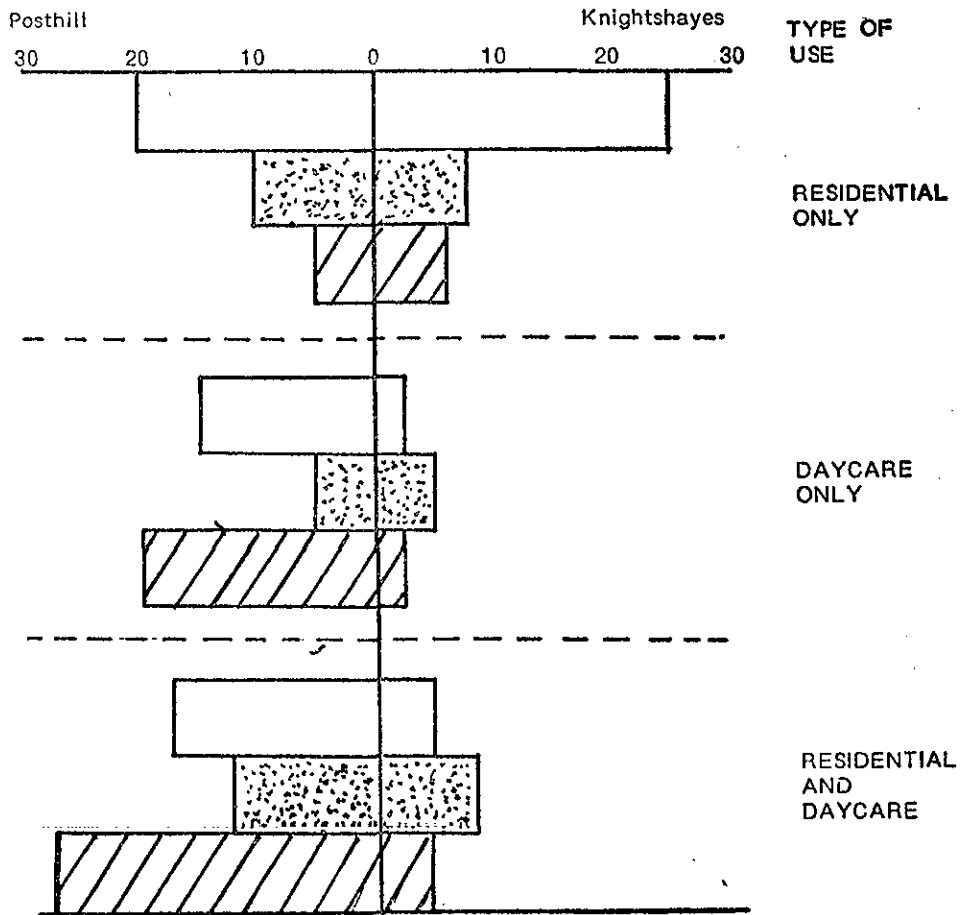
1. **SURVEY** – A ten-part questionnaire was devised which was completed by the team leaders in the units to provide factual information on the extent and type of usage. In this way, for each person who had used the unit, information was gathered on the reasons for use, type of use – accommodation or day-care, facilities used, pattern of use – length and frequency, and other details such as the home circumstances.
2. **OBSERVATION AND DISCUSSION WITH THE UNIT STAFF** – This consisted of participant observation and informal discussions with staff. The scope of the investigation was open-ended but important points of focus were: staff perceptions of the unit's effectiveness in meeting the needs of users and their families, the role of the units, their accessibility, and ideas about future developments.

A crucial aspect of the observation was an assessment of the quality of the experience for clients including the extent of institutionalisation, normalisation and client's personal development. Five categories, employed by Moulin (1985) and Wing and Olsen (1979) to give an indication of the quality of life of an institution, were used to structure the observations and discussions. These cover the experience of a facility in terms of the following categories: Homely, Personal, Client centred, Accessible, Openness.

In addition the staff were asked open-ended queries about the quality of client's experience in the units.

3. **FAMILY INTERVIEWS** – Twenty-four interviews were carried out with the families or care-givers of clients who had used the units (twelve from each unit). Selection was based on providing a wide sample of clients in terms of their ages, types of handicap, and home circumstances. A semi-structured interview format was employed for the interviews which were conducted in the client's homes or previous homes if they were residing in the units. Like the interviews with the staff this utilised Moulin's categories. It also focussed on the perceived reasons for use of the unit, perceptions of the unit's role, and the unit environment, the perceived benefits for the client and their family, suggestions and criticisms, and indication of future use. Nine of the interviews were videotaped with the families' consent.

Comparison of Usage: Posthill and Knightshayes (Fig. 2)



KEY:



Number of clients

Length of stay in days

Frequency of use

## RESULTS

The results of the survey indicated that a primary use of both units had been to provide temporary accommodation, mainly for respite. Knightshayes, the unit located in an urban setting in Exeter, showed a faster turn-round in that their clients used the units less frequently and for shorter periods than those of its rural counterpart, Posthill (see Fig. 2).

One of the main reasons for the slower turn-round of clients at Posthill was because it had a commitment to providing regular day-care for social training and occupational therapy. Consistent with this there is a greater emphasis on behavioural treatment in the form of individual training programmes, devised by the staff for each client. Knightshayes on the other hand showed an emphasis on medical treatment and assessment.

Both units have had to offer long-term accommodation (4 months plus) for some clients who could not be cared for elsewhere. This has severely restricted their flexibility (up to 40% of beds taken up). Despite this the units had been able to develop effective solutions such as working carefully with voluntary resources and planning client's stays carefully.

A major overall finding from the participant observation and discussion with staff was that the units had succeeded in breaking away from the institutionalised, hospital model. They are run on the lines of a family home in which the activities revolve around the kitchen where food bought jointly by staff and clients is prepared together, and the lounge where staff and clients chat, watch television and generally entertain each other. The atmosphere is friendly with absence of rigid rules. Clients are treated as individuals and have their own rooms, their own possessions and are encouraged to make their own decisions wherever possible. There is considerable flexibility in the routine with impromptu outings, snacks and choice over meal and bed times.

*Staff considered that the quality of the experience for clients was high. This was especially the case for staff who had worked in hospital situations previously and therefore had a clear basis for comparison.*

The interviews with the families and the unit staff confirmed these views and indicated that these aspects of the units were recognised and valued highly by the families. The families were also asked what aspects of the units corresponded to each category, for example; in what ways they regarded the units as homely or institutional. A summary of these responses is given in Table 1 :

It was notable that the favourable opinions given were in marked contrast to those about other institutions that they had used previously. Likewise staff universally stated that the units were superior on these dimensions to hospitals and other settings in which they had worked. The evidence clearly indicated that the quality of the experience for clients (and staff) was superior to large hospital settings.

Generally staff morale was high, though obviously there were some reservations and criticisms voiced. Primarily these were to do with some confusion felt about their roles, namely, the balance between domestic, nursing, training and therapeutic duties.

One of the main differences between the units was in the way that they had evolved. Posthill with its rural and relatively isolated location had developed to provide a wide-ranging 'global' service. This was primarily because of the lack of other local resources. As a consequence it was much bigger and attempted to provide a cross between a small hospital and 'village community' structure with workshops and a number of small enterprises such as a fancy-dress costume production and hire service.

**Table 1**

**Responses offered by the families interviewed according to the categories used in assessment of quality of life in the L.S.U.s**

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1. Homely	<ul style="list-style-type: none"><li>- Small number of clients.</li><li>- Food, joint purchasing, preparation, consumption with staff.</li><li>- Own rooms.</li><li>- Own possessions.</li><li>- Layout of house like a family home.</li></ul>
2. Personal	<ul style="list-style-type: none"><li>- Knowledge of clients' needs, interests.</li><li>- Maintenance of contact with clients when not using L.S.U.</li><li>- Knowledge of family circumstances.</li><li>- Polite, friendly staff.</li><li>- Highly staffed, therefore time for 1 to 1.</li></ul>
3. Client Centred	<ul style="list-style-type: none"><li>- Flexibility about times, e.g. bed and meal times.</li><li>- No unnecessary rules or regulations.</li><li>- Non punitive - families felt safe about leaving their relative.</li></ul>
4. Accessibility	<ul style="list-style-type: none"><li>- Contact at any time, e.g. crisis, which is reassuring.</li><li>- Encouraged to use Unit if any difficulties arose.</li><li>- Easy to get clients in for respite, short-term care, etc.</li></ul>
5. Openness	<ul style="list-style-type: none"><li>- Encouraged to visit.</li><li>- Felt able to express views/opinions.</li><li>- Staff friendly, not hierarchical.</li><li>- Did not feel anything was being hidden or concealed.</li><li>- Encouraged to participate in decisions about clients. The only exceptions to this were families where the client was a long-term resident and they had infrequent contact (less than 1 and 2 weeks).</li></ul>

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A contrast between the units was the concern that a degree of institutionalisation was beginning to creep in at Posthill. For example the difficulties in arranging transport for outings and shopping meant that food buying was being done in bulk rather than on a small-scale basis which is more appropriate to the development of independent living. On the other hand there were some difficulties regarding the training opportunities at Knightshayes where due to the more rapid turn-round of clients it was difficult to develop and implement such programmes. In effect there was an apparent trade-off between the size of unit, range of services possible and level of institutionalisation.

At both units there was a growing recognition of the need to work closely with families in order to establish and maintain training. Some difficulties here were noted such as cases where the staff developed, for example, a programme to teach spoon feeding but the family were not co-operative and did not continue the programme when the client was at home. Such cases add support to Burden's (1979) comments regarding the need to work closely and sensitively with families in order to maintain a consistency in approach between the unit and the family home.

Overall one of the most valuable aspects of both units was seen as the provision of a constructive form of respite. This is illustrated in Table 2 which shows comparisons between the perceptions of twelve families from each unit and the corresponding perceptions of the unit team-leader for each client. (Family and staff were asked to select the major reasons for using the units from a given set).

**Table 2**  
**Primary Reasons Given by Families/Carers for Using the LSUs**  
**A Comparison of Staff and Family's Perceptions \***

Reasons given for use	POSTHILL		KNIGHTSHAYES	
	Family N =-12	Team** Leader	Family N =-12	Team** Leader
Respite – break for relief and special occasions, holidays, anniversaries etc.	10	6	8	8
Programmed short-term care. Stimulation – something to do, including OT and social contact.	11	3	9	2
Assessment – physical and psychological Also especially relating to future accommodation.	6	8	5	5
Encourage independence social and practical. Often generally described as 'weaning'.	8	3	10	1
Behavioural Treatment.	2	6	3	4
Crisis including illness in the carers.	2	2	5	1
Medical Treatment	2	3	6	7
Accommodation – seen as place to live but all families recognised it was not permanent.	2	2	2	2
Prevention of further crisis.	0	0	2	0

\* Major reasons given by the twelve families and team leaders. Number of choices was not limited (max. possible was 9, e.g. if client made use of all of the facilities above).

\*\* Team Leaders comments in consultation with their staff.

Generally the families saw the units as having a broader range of inputs for their relative than the staff. This is mainly explained by the family's emphasis on the value of the units in encouraging their relatives to become more independent (see Table 2 – Encourage independence . .) and as somewhere that they could make friends and be usefully occupied (Programmed short-term care). There was agreement in seeing the units as accessible. For families this availability at any time was seen as extremely reassuring, especially for families with violent or medically

unstable relatives. This was particularly evident at Knightshayes where crisis was seen as important by the families as a reason for use. All families stated that their relatives enjoyed their stays at the units, whether on a daily or a residential basis and they felt happy about them attending.

A further difference between staff and family's perceptions was that the staff regarded the units in more instrumental terms as providing behavioural treatment and slightly more emphasis on medical treatment. However there was general agreement that the units provided assessment.

#### **Leaving-home and independence.**

There was a significant positive side-effect of the use of the units for respite and for planned short-term care. It emerged from the interviews and discussions with the staff that the units were serving a most important function in facilitating the transition of some clients from the family home to living independently in the community. Many families stated that the units were somewhere that their relative could make friends and have some social life. From the interviews it was also clear that most of the clients were still occupying a child role in their families even in one case where the client was over forty years old. The pervasiveness of this issue was also powerfully illustrated by the fact that all of the families referred to their mentally handicapped relative as a 'child'. This tendency to employ a variety of strategies to deny the reality of the handicap has been elegantly described by Pollner and Wikler (1985). The following extract illustrates some of these points. (Nicola, a young woman with Down's syndrome, was aged 32.)

Interviewer: 'What does Nicola gain most from attending the unit in your opinion?'

Mother: 'Well, I think she likes everybody and its very nice for her to be with the other children.'

Father: 'Yes that's right, she gets a bit fed up with us at home all the time and it's good for her to be able to play and be with the other children isn't it? Well I think so anyway. Its's not that we want to get rid of her, but she gets a bit fed up.'

Interviewer: 'Have you noticed any changes in Nicola since she's been attending the unit?'

Mother: 'Well I think she can do more for herself now . . . Yes she's become more independent . . . I think sometimes she doesn't want to come back here with us at all . . . (laughter)'.

It was significant however that the families were unanimous that the units had encouraged their handicapped relative to become more independent both in terms of physical skills such as bed-making, washing and also emotionally. However it should also be noted in this context that the unfortunate title of 'house-parents' had been chosen for the staff in the units which served to confirm this perception of clients as 'children'.

A related finding was that the units could be employed imaginatively to prevent crisis in the families. For example, a strategic programme of respite was in some cases devised to break up self-perpetuating cycles of use initiated by crisis. This also had important benefits for minimising the parents' feelings of guilt regarding the placement of their relative in the unit. It also reduced the likelihood of criticism by the staff and the possible development of hostility and competitive parenting between the staff and family. For example, one family had, despite major difficulties over the years, made a decision to keep their son Alan at home. Now aged 24 he periodically became abusive, threatening and occasionally violent

towards his parents. At this point the unit would be contacted and Alan would move in for a few weeks. Within the space of a few days at the unit he became calm and settled down. Though this was satisfactory for Alan and the staff it left the parents feeling inadequate and at fault. Eventually Alan returned home and showed resentment at having been 'sent away'. In turn the parents were unable to exercise any consistent discipline because they felt guilty about rejecting him and despite being extremely upset and angry with Alan they excused his threatening behaviour as the result of his being 'upset' and 'hurt'. Naturally enough in the face of these ambivalent circumstances Alan soon became problematic again. Furthermore there was a danger that antipathy was developing between the staff and parents. For example the parents, due to their feelings of failure and guilt, were becoming wary of the staff, who in turn were tending to misconstrue this as hostility towards them.

The following is an excerpt from the interview with this family:

Interviewer: 'You were saying that it's good for Alan (son) to have a break from you, get used to being away.'

Mother: 'You see, to Alan if he's been home for five or six weeks, he's had enough of us. If he has a change and then he comes back, he reacts back on us again because he thinks we've put him away . . . He don't accept the break until a long time after.'

Father: 'He'll say I'm only going up there for a week. I'm coming back again.'

Interviewer: 'Would you find it helpful if Knightshayes or somewhere like Knightshayes got him used to having a broak?'

Father: 'It would be the biggest help of the lot to us.'

Interviewer: 'Do these outbursts (son's) come about when he is wanting his own way?'

Mother: 'Teenagers'

Father: 'That's right, when he wants his own way. If something doesn't go his own way he will play on it.'

Mother: 'But when he's been with somebody else, there's no outbursts at all. But after a while with them he starts to react the same as he would to us. So we've proved to ourselves now that it's not just us . . . He wouldn't do it at Knightshayes with just a weeks holiday . . . But after they get to know him a while, it just happens.'

An important intervention into cycles like the above is to separate the admission to the unit from the crisis point in the family. In this case by providing access to the unit at regular planned intervals, 'programmed short-term care', the self-perpetuating cycle was disrupted.

## CONCLUSIONS

The units were found to be providing a valuable service for clients and their families, the quality of which was accurately perceived and acknowledged by them. The broad hypotheses guiding the study were verified. An ecological model with an emphasis on flexibility in responding to changing needs was found to be appropriate. It was indicated by the staff and family's comments that a homely non-institutionalised type of unit was appreciated. Most importantly such an atmos-

phere made it easier for families to 'let go' of their son or daughter without feeling excessively guilty or anxious.

From the interviews it was clear that independence and leaving-home were vital issues for the mentally handicapped people and their families in the sample studied. It is suggested here that the provision of effective support for families in the community must take careful account of these issues if families are not to become over-burdened to the point of collapsing. This, apart from being an unethical way to proceed, in the long-term puts greater demands on other resources. It is suggested that the units studied, and other varieties of support that are being developed in the community, should incorporate into their work the problem of easing the transition of the handicapped person from the family to living independently in the community.

The evolution of these units raises some general issues for similar developments in other Regions. The involvement in the leaving-home transition was not originally envisaged as a central part of their role nor was the provision of long-stay accommodation for clients who need intensive care and cannot easily be accommodated elsewhere. As regards the former there is a potential dilemma in that by offering short-term support and respite the units may actually perpetuate the accommodation of the client in the family home. Despite potential economic savings for the Health District this may retard rather than promote the normal developmental processes. On the other hand the two aims: of relieving the burden on a family and promoting eventual independence of the handicapped person, can be effectively combined. Clear planning by the Community Mental Handicap Team can employ the units to ease the family situation which consequently allows the eventual transition to be made in a rational manner within a relatively stress-free situation rather than in a hasty and panicky way as a result of stress and crisis at home.

Regarding long-stay clients there is a need for the provision of alternative facilities and formulating plans for them early in the development of services. An unfortunate consequence of not doing so is that the units lose their flexibility and ability to provide a wide-ranging service to the community.

One direct outcome of this study has been the development of family-interviews and family-staff counselling sessions at Knightshayes. The indications are that this is valuable and will form an important part of the work of the units. The details of this exploratory work are being prepared for publication.

### **Acknowledgments**

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