

SHORT-TERM CARE FOR MENTALLY HANDICAPPED CHILDREN AND ADULTS: A STUDY OF AVAILABILITY AND USE

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INTRODUCTION

The beginning of the last decade in Britain saw a minor revolution within the administration and organisation of social welfare services. This period witnessed the evolution of Social Service Departments, the re-modelling of the NHS, the re-organisation of local government boundaries and several policy initiatives relevant to particular client groups. One of these was the Government White Paper "Better Services for the Mentally Handicapped" (Cmd 4683, HMSO) which introduced a new move towards community-based services, expressing an emphasis on non-institutional care, greater support to families caring for a handicapped child and wider provision in day care and assessment facilities. In the light of these developments the Sheffield Development Project (SDP) was set up following the publication of the Feasibility Study Report (FSR) by the Department of Health and Social Security (1971) recommending provision of a comprehensive pattern of services for mentally handicapped children and adults. The Project has since become widely recognised in terms of the new concepts in service delivery that it was designed to test. Essentially it consisted of a range of services such as hospital units, hospital hostels, group homes, assessment units for children and adults and specialist social workers, that were to be made available through the existing network of welfare-providing agencies (Heron and Phillips, 1977).

Various criticisms, however, have been made of the Project, focussing, in particular, on the lack of co-ordination between the participant service organisations and the inadequate role definition of many of the service components (Malin and Race, 1979). Another relevant factor is that resources made available through the SDP were mainly in the form of capital developments, *i.e.* buildings, than through the provision of actual services. At the operational level several of the intended developments never occurred due to inadequate funding, and confusion over relative administrative responsibilities. In particular this has affected residential care provision resulting in too few places becoming available and hence the failure to close, as intended, some of the old hospital units. The current position is, quite simply, that the system cannot easily adjust to any new demands, so that whenever a family crisis occurs then the most likely response is for a bed to be provided for the handicapped person in a traditional hospital unit rather than in a place possibly more suitable.

In spite of a failure by the Project's designers to spell out clearly the operational arrangements for both day and residential units, significant developments have taken place in recent years largely through the efforts of committed individual professionals employed within the service. One example of innovation has been the varying attempts on the part of all three agencies — health, social service, education — to provide short-term care (STC)*. No explicit recommendations were made by the FSR to provide this form of care although it was recognised that, in the case of children, a few places (say 8 or 9) should be allocated from within other longstay accommodation. The growing need to provide temporary relief to parents in caring for their mentally handicapped offspring can be recognised at two levels: firstly there is the notion that by making such relief readily accessible to parents, the demand for a future more permanent form of care can be postponed and secondly that the provision of short term respite to relatives caring for a mentally handicapped person should be an entitlement simply because they are the main providers of day to day care.

* This is care provided for short periods eg a week, weekend, holiday period to enable parents to have a 'break'.

Set in a national context it is clear that some STC provisions have already been made. For example, special purpose units have been reported in a small number of areas (eg Reading, Exeter). The National Development Group for the Mentally Handicapped (1977) proposed a marked national extension of STC provision but there is little evidence to show that local policies have reflected this acknowledged latent demand for places. Across the country, however, there is a range of provision but this is based mainly on longstay units run by the health and local authority services. The shortstay home at Reading (Klein, 1979) is exceptional insofar as it is able to cater for all types of severely mentally handicapped children, possibly owing to the multidisciplinary expertise offered by available staff. In addition, several areas have developed their own fostering schemes for mentally handicapped children though no such arrangements are currently known that provide for adults. Both the Leeds and Northumberland schemes, for example, are able to cater for severely mentally handicapped children who may have additional physical or multiple handicaps. Such schemes have emerged through the appointment of a selected group of foster parents who may be able to offer a home to a child for a fixed period of time, usually from a weekend up to a fortnight. The intention has been to provide the parents of the mentally handicapped with a break, to make the service readily accessible 'on demand', and to provide an opportunity for the mentally handicapped child to develop relationships with other people outside of the family setting.

The purpose of this present study was twofold: to ascertain existing provision of STC facilities within the residential units for mentally handicapped children and adults in the Sheffield area and to consider the attitudes of parents towards such provision. For the second part it was felt necessary to include both parents who had made use of such provision and those who had not in order to determine, if possible, what specific factors had encouraged use. An overall aim was to ascertain the extent to which existing provisions met expressed demand and to quantify this demand in such a way that service units may be able henceforth to adjust their resources accordingly. It is extremely difficult, however, to measure a concept such as demand for STC when parents' views are naturally coloured by their experience of known available services and an inevitable reluctance, in some cases, to admit a need for professional help. Non-users, in particular, often fail to see the potential of STC resources, and this factor may be major in accurately determining the extent of overall need.

METHOD

The data were gathered through interviews with potential suppliers and users of the service. The suppliers side was approached at two levels: at the policy/administrative level and via the heads of all residential units. Interviews were arranged with appropriate senior officers in the health, educational and social services in order to establish, if possible, whatever policy governed the provision of STC by the service concerned and to obtain official approval for an approach to unit heads. For health, the officers seen were the two consultant psychiatrists, the divisional nursing officer, and the sector administrator in mental handicap. Education was represented by the Assistant Education Officer (Special Education), and the Social Services Department (F and CS) by the Director of Social Services. Heads of individual residential units were then approached; these units comprised the following:

Health: 7 hospitals, 7 hostels
Education: 1 shortstay home
Social Services: 9 hostels

Potential users were determined through a sampling of all families resident in the Sheffield Metropolitan District with a member of the family living at home who was recognised as being mentally or multiply handicapped. Staff and time resources on the part of the research workers restricted the number of possible interviews to around one hundred, hence some stratification was seen as essential, this being by area of residence within the city and age of the handicapped person. The sampling frame was limited to families with a

severely mentally or multiply handicapped member who was known to the Sheffield Case Register. The three areas of residence chosen had been previously determined by the Case Register (Martindale, 1980) using a postal district mode of distribution and data from the Registrar General's census resulting in the following broad categories of housing: 'prime residential areas' (A) = private housing of good quality, high rise blocks and older council house property (B) and intermediate property in terms of accommodation and social class mix (C). Age strata were pre-school age and adult. For the pre-school group there was no requirement to sample as the total number available from homes in the three selected postal districts was only ten children. The sampling fractions for the school age and adult groups were 1 in 3 and 1 in 2 respectively.

Having ascertained the sample of potential users through the means of the Sheffield Case Register, these families were approached for interview. Out of 107, 103 agreed to be interviewed — 2 had moved away and 2 refused. Both written refusals showed a clear negative interest on the part of parents in the whole issue of STC.

The final distribution of home interviews is set out in *Table 1*.

TABLE 1
Home interviews, by area of residence and age of mentally handicapped person

Age Group	Residential Area			Total
	A	B	C	
Pre-school	1	6	3	10
School-age	9	17	13	39
Adult	12	26	16	54
Total	22	49	32	103

MAIN FINDINGS

Probably the most significant factor emerging from discussions with senior officers in the three services was that there was no co-ordination between them in the area of STC. The three services offered parallel facilities in some areas and there was no evidence of systematic interchange or discussions concerning requests for STC. Also there was no suggestion made that future meetings were planned to exchange ideas or to evolve an overall area policy.

INTERVIEWS WITH UNIT HEADS — THE PATTERN OF SUPPLY

The approximate numbers of beds available (based on information provided at the time of interview in late 1979 and early 1980) are set out in *Table 2*. Nineteen unit heads said that the number of beds available varied, and fourteen that sometimes none were. Two hospitals and all but one of the health and social services hostels for adults were unable to offer STC to the non-ambulant multiply-handicapped.

TABLE 2
Approximate numbers of beds available for STC use

	Health		Social Services Hostels	Education	TOTAL
	Hospitals	Hostels			
Adults	7	8	16	—	31
Children	14	—	28	10	52
	21	8	44	10	83

The various explanations given by the twenty-four unit heads for the number of beds (fixed or variable) for STC used are summarised in *Table 3*. The stated length of stay on an STC basis ranged from one night to three months (with one or two exceptions up to as long as a year).

TABLE 3
Explanation for fixed or variable availability of STC beds

	All beds STC	Use does not vary	Can use vacant bed for STC	Use LTC bed for STC when resident on holiday	Put up extra bed for STC	Space problems	STC bed used for LTC	Total
NHS Hospital	0	1	6	0	0	1	0	8
NHS Hostels	0	1	3	2	1	0	0	7
FCS Hostels	1	3	4	0	0	0	1	9
Education	1	0	0	0	0	0	0	1
	2	5	13	2	1	1	1	25

In 24 of the 25 units short-term residents were not separated from long-stay residents, but in one social service hostel the short-termers were put in the wing where the more dependent long-stay residents lived, as it was felt that the short-termers might need more help and supervision. In the residential section of one social services unit the emergency beds for the under-fives were separate from the STC beds for the physically handicapped.

Although units often were unable to offer STC, some would go part way to offering relief for families by providing day care. Some units offered a full day-care service, while others often had an adult or child for a few hours after training centre or school, giving them their tea. They would be collected later in the evening by a relative. Eleven of the twenty-five units operated on this kind of informal basis (in addition to the one hospital and one hostel that offered a formal full-day service).

The majority (four-fifths) of the reasons given for requesting STC could be covered by three main headings: illness or death of a parent (one-quarter); to cover the period of the family Holidays (one-third); and to afford the parents some temporary relief (one-quarter). Most STC requests — when the parents do not already have direct contact with a unit previously used — were made through the consultants in the health service, and through the allocation panel in the social services.

INTERVIEWS WITH PARENTS — THE PATTERN OF DEMAND

Users and non-users — Exactly half the homes in the sample had never used STC. There was no difference in this respect so far as residential area (see *Table 1*) was concerned, but usage/non-usage was clearly related to the age of mentally handicapped children, as shown in *Table 4*.

TABLE 4
Usage/non-usage of STC by age groups

	Pre-school	School-age	Adult	Total
Used	1	26	24	51
Never Used	9	15	28	52
Total	10	41	52	103

There was no sex difference in usage, but non-user mothers tended to be older, as shown in *Table 5*. Three-quarters of the non-user group as compared with just over half the user group were either the only child at home or one of two.

TABLE 5
Usage/non-usage by age of mother

	Age of Mother			Total
	25-40	41-54	55+	
Used	18	19	14	51
Never Used	12	19	21	52
Total	30	38	35	103

Comparisons between the groups on various dependency criteria are shown in *Table 6*. It is apparent that the user group contained more dependent members than the non-user groups, three-quarters of which "had no significant problems parents could not cope with". Answers to another question suggested the likelihood that the reasons for non-use of STC by the remaining quarter included "disliking the idea of sending N away".

TABLE 6
Usage/non-usage in relation to dependency

	Users	Non-users
Non-ambulant	12	8
Incontinent	21	14
No speech	23	18
Severe handicap	51	43
Severe behavioural problems	16	5

USERS

It was clearly possible to distinguish four categories of frequency of use: 'once only'; 'once annually'; 'irregular'; 'very regular'.

- a) **Once only:** In five instances, parents has used STC once because they had only needed it on that one occasion. In four of these cases, STC had been used because the mother or father was ill or in hospital. In the remaining case the parents had separated, and the father had not realised his son was in short-stay; when he found out he took him out of care.
- b) **Once annually:** Eight families used STC once every year for the annual holidays or a break. Two of these had always used the Education Department's short-stay home and had not at the time of interview been able to make arrangements for short-term care this summer. This group provided the only example of a social worker arranging for a young girl to go into a health service hostel. In all other placements the short-term care was arranged by the health service in health service accommodation, and by social workers in social service accommodation.
- c) **Irregular:** Eighteen of the families used STC irregularly and there was no identifiable pattern to this use. In sixteen cases parents had used STC "for a break", or when they had been ill or in hospital. In one case a young mentally handicapped adult had asked to go into short-term care himself, and in another the parents had used STC when they were moving house. These eighteen families had used short-term care on average four times each, and eleven of them had used several units. In one case the young adult had now become a long-term resident, as she preferred to live in the hostel and her parents were elderly.

- d) **Very regular:** Twenty families used STC very regularly, and it could be called part of their "structure for coping". One mother said she used STC "as often as I can". Most of these families found it difficult to say how often they had used short-term care, simply because they had used it so often over the years. In all cases short-term care was used to give the parents a break but also for many other reasons: for example, when parents were ill, or to enable them to go to a family wedding.

NON-USERS

All fifty-two families in the non-user group were asked if they had heard of short-term care: four families had not. In two cases the mothers were not English; in one of these the mother spoke a little English but the other mother spoke no English, and her 16 year old son interpreted for her. Neither family had any contacts with social workers and both led very isolated lives in very poor areas, one in the only inhabited house in a street due for demolition.

The other two families who had not heard of STC had mentally handicapped sons who were over 30 years of age. In one case the son was out every night at Gateway, football and the Speedway and was very independent. The elderly parents never went out in the evenings or visited the adult training centre in the daytime. The parents in the other family were also very elderly and in poor health, the father in fact bedridden. In this instance, the mentally handicapped son looked after his aged parents, lifting his father out of bed and in and out of the bath, shopping and doing the heavy housework. In fact he kept the family together as a unit.

DISCUSSION

This study examined both short-term care provisions within the Sheffield area for mentally handicapped children and adults and parental attitudes towards this type of provision in order to make some assessment of the effectiveness of the service as a whole. It is essential to determine on the basis of studies of this type what possible options for improvement can be made available.

SUPPLY OF STC

The overall results appear to justify the following statements:

1. Mental handicap units in the Sheffield AHA did not at the time of interview have any positive policy for adult STC, nor for children other than those who had a direct connection with a particular new hospital unit. Availability of places was largely determined by the chance occurrence of empty beds in the long-stay hospitals and hostels. Despite the fact that these were all medical units, the available STC places for multiply-handicapped non-ambulant adults were few: the reasons given were shortage of suitable staff, pressure from closure of older hospitals, and suitable building design.
2. Five adult hostels operated by Sheffield Social Services provide between them a minimum of eight designated STC beds: this total can be increased by the temporary availability of long-stay beds. The principals of these hostels meet regularly as an allocation panel (for both long-stay and STC residence). The group of hostels maintains (by rota) one emergency STC bed, available for 72 hours. None of these hostels can accept multiply handicapped non-ambulant residents, or those requiring nursing or medical care.
3. There has been no effort to achieve inter-service co-ordination of STC supply nor to test out whether present level of supply matches up with expressed demand. In none of the three services has it been perceived as important to make known to parents the potentially available STC, or to develop it as a significant supportive service to the families of mentally or multiply handicapped people.

DETERMINANTS OF DEMAND

1. Systematic differences between 'User' (U) and Non-user' (N) groups of families

- a) Nearly two-thirds of the school-age children were in U families.
- b) Relatively more younger mothers (25-40) were in U families and relatively more older ones (55+) were in N families: the figures for the middle age-groups were identical.
- c) The dependency level of those in the U group was clearly higher than for the N's; this was also very marked in respect of 'severe behavioural problems' where STC was used by sixteen of the twenty-one families concerned. Four-fifths of the N group parents, as compared with two-fifths of the U's, felt able, when necessary, to leave the mentally handicapped person alone at home.
- d) Three-quarters of the N group received help from relatives, compared with one-half of the U group. This type of help also seemed to be perceived as more supportive by the N group recipients.

Clearly, not all of these differences between U and N groups can legitimately be regarded as possible determinants of demand. For example, greater usage of STC by school-age children may be to some extent a consequence of greater and easier availability, through the existence of the LEA short-stay home. It does, nonetheless, make sense to find usage related to factors such as family size, level of dependency of the handicapped person and available support provided through informal networks.

2. Factors encouraging and discouraging use

Certain factors appeared significant in this respect. In the case of the first, ease of arrangement was a promoting factor: this characterised the STC available for children, both at the new hospital unit and at the LEA short-stay home, and for adults, at the social service hostels through the existing allocation procedure. Becoming a 'regular' had its advantages in about half the U families and meant that regular arrangements were possible with individual units for those families concerned. Furthermore, the availability of information on STC provided a positive reference point for parents considering using this resource.

Other factors appeared to discourage use, such as the lack of appropriate initiating action on the part of the majority of providing units. Many adult units, for example, were either unable or unwilling to accept non-ambulant or 'difficult' cases. The absence of co-ordination among providing services often meant that a more appropriate form of care became sacrificed for the only type able to be provided by the referent agency. The adult side in particular depended largely on 'casual vacancies' within the long-stay system of care and such vacancies determined the nature of many individual placements. Poor contacts between parents and professionals militated against a choice of appropriate STC owing primarily to the lack of information on client needs in terms of effective and professional support and help.

Taking these factors overall, the evidence justifies a conclusion that STC had not yet been recognised in the relevant agencies as an essential element in a total provision of a community-orientated mental handicap serviced. The apparent reluctance to 'advertise' it to parents may be understandable in the light of staffing and building problems, but the absence of a definite policy and of intra- and inter-service co-ordination cannot be so readily explained.

Most parents, even in the U group, strongly believed that it was their duty to care *personally* for their mentally handicapped son or daughter; and though willing to accept the right kind of support from within their wider family group they sometimes felt 'guilty' accepting outside help from the official support network. This underlines the need for agencies to initiate an approach to parents, to offer an acceptable and appropriate type of service and to convince parents of the benefits that it will bring. The evidence obtained from the U group parents made it clear that such negative feelings and attitudes could be overcome; unfortunately for most of them the opportunity for this to occur did not arise until they were at breaking point and desperate.

A distinction is urgently required to be made between apparent 'demand' for STC and the latent 'need' for it. Need is usually greater than demand mainly because the parents and relatives of mentally handicapped people feel guilty about seeking or using STC in order to give themselves a 'break' from the constant strain of caring and coping. User parents were brought into a positive frame of mind about STC mainly by becoming familiar with a single unit, not by the possible availability 'somewhere' of a bed temporarily empty in a long-stay residential unit.

Overall there is a need for more provision in this field, but an *a priori* case to consider each 'need for care' on its merits. This applies both to those clients already in permanent care and to those being cared for at home. Thus the general question arises as to what extent is it feasible for STC to provide an acceptable substitute for long-term care. The guiding principle should be to provide an acceptable form of care to aid parents, which may mean back-up support provided through means other than residential care of either a short or long term nature.