Bringing mentally handicapped children out of hospital

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Front cover

The King’s Fund Project Paper Number 30
November 1981
Bringing mentally handicapped children out of hospital.

The cover features a black line drawing of a street where a person in a wheelchair is purchasing fruit and vegetables. They have a number of grocery bags next to the chair, and someone is helping them count out the money in their hand.

Inner front cover

King Edward's Hospital Fund for London is an independent charity founded in 1897 and incorporated by Act of Parliament. It seeks to encourage good practice and innovation in health care through research, experiment, education and direct grants.

The King's Fund Centre was established in 1963 to provide an information service and a forum for discussion of hospital problems and for the advancement of inquiry, experiment and the formation of new ideas. The Centre now has a broader interest in problems of health and related social care and its permanent accommodation in Camden Town has excellent facilities for conferences and meetings. Allied to the Centre's work is the Fund's Project Committee which sponsors work of an experimental nature.

One important focus for the Centre's work in recent years has been the practical steps necessary to develop comprehensive community-based services for mentally handicapped people and their families. In parallel with the present paper, the Centre has already published An Ordinary Life (Project Paper No. 24, February 1980, £1.25 incl. p&p) describing the planning of residential services, and Short Term Care for Mentally Handicapped Children (February 1981, 65p. incl. p&p) a discussion paper on good practices in providing short term residential care.

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Title page

Bringing mentally handicapped children out of hospital
by Ann Shearer
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Foreword

Last December, Patrick Jenkin stated unequivocally that large hospitals do not provide the right environment for mentally handicapped children to grow up in. He then went on to describe the practical steps which the Government intended to take to help get the remaining 3,000 or so children into a more suitable environment. One of these was to hold the conference which provides the basis for this admirable report.

As Ann Shearer demonstrates so vividly, there are many and varied views on what the alternatives to hospital care should be for mentally handicapped children who need long term residential care. Ideally, as for all children, we would wish that it was possible for them to be brought up in their own homes and that parents could be provided with the range of services that would enable them both to cope with the additional problems that a handicap presents and to feel assured that their child was being developed to his full potential. We are all agreed that where, for whatever reason, this is not possible and the child's needs would be best served by some form of residential care, that care should be given in a small, homely setting. The purpose of the conference that my Department sponsored in June at the King's Fund Centre was to enable different authorities—health, local and voluntary—to demonstrate feasible alternatives to hospital care for children whose needs could not be met at home. I am sure that those who attended the conference will share my feeling that it was a rewarding and moving occasion. I must give just one example: the ordinary terrace house in Ashington, Northumbria, which now provides a real home for children from Northgate Hospital. As Julie's mother said, "it's the smell of baking that greets you when you go in, instead of the smell of disinfectant that hits you on the hospital ward". And it is worth noting that setting up this new home was a health service initiative and the leader of the staff is a nurse from Northgate.

In planning the conference, we were clear that we needed to make a report of its proceedings available to all concerned with services for mentally handicapped children. This is why the Department with the assistance of the King's Fund Centre commissioned Ann Shearer to produce her independent account. I think all those who read this highly encouraging and moving account oi the various schemes will agree with me that she has done an excellent job.

It is relatively easy to pick out bad points in any service and make news of them. I therefore welcome this opportunity to draw attention to some of the good things that are going on—in the health service and elsewhere—to give our mentally handicapped children a better quality of life.

Sir George Young
Parliamentary Under Secretary of State
Department of Health and Social Security

Introduction

“The time has come to state unequivocally that large hospitals do not provide a favourable environment for a mentally handicapped child to grow up in. I can think of no more important aim than to try to ensure that all children who do not need specialised health care have the chance to grow up and develop to the best of their potential in their own homes or in small homes in the community.”
Patrick Jenkin, Secretary of State for Social Services
10th December 1980

This report grew out of a conference organised by the King's Fund Centre in June, 1981, in cooperation with the Department of Health and Social Security. The conference itself grew out of a speech six months earlier by Patrick Jenkin, in which he made the strongest official commitment for a decade to finding alternatives to existing hospital wards for children who cannot live with their own families. Exploring those alternatives for the children now in hospitals was what the conference was about.

The Government had already provided one impetus, by offering £1m, spread over four years, to voluntary organisations which wanted to bring children out of mental handicap hospitals and could match its contribution pound for pound. But as Sir George Young made clear at the June conference, this scheme is only intended to supplement what statutory authorities provide. So this report draws on examples from health and social services authorities as well as the voluntary sector, to show what can be done.

The numbers involved

In sheer terms of numbers, creating alternatives to mental handicap hospital wards can hardly be said to present health and social services planners with one of their more daunting tasks. Those wards are still being used for children—and increasingly. The number of admissions to them of children under 16 rose from 5956 in 1977 to 6628 in 1979. But the number of discharges rose too, from 5628 to 6459. The vast majority of those children had been in hospital for less than a month.

At the same time, the number of children for whom a hospital ward must be home has fallen far more sharply than.was officially predicted. In 1969, there were 7100 of them, and the 1971 White Paper Better Services for the Mentally Handicapped said that 6400 places would be needed by 1991.Yet at the end of 1979, there were only 2839 children under 16 living in mental handicap hospitals and units across the country. The 1991 target has since been reset to 5200, to take account of population changes. But this figure still looks like a wild overestimate, as Patrick Jenkin acknowledged in his December 1980 speech. "It is now clear", he said then, "that the White Paper target for hospital places for children was too high and authorities should not plan in the longer term for more than the current level of provision."

So the current situation is somewhat paradoxical. As more and more children stay at home with their families, the use of the hospitals has increased for them: the wards have become a major resource for short-term relief care. But at the same time, the number of children who live in hospital is falling fast. If present trends continue, it's been predicted, there will be no children left living in hospital at all by 1986/7.

Just how small their numbers already are emerges more clearly when the national figures are broken down. In one of the most thorough searches yet done, for instance, MIND found 132 children under 16 in the hospitals of the North West Region in 1980. A study for Guy's health district in South London published in 1981 found that 105 out of a total of 133 children under 16 were living at home, and only 8 in a mental handicap hospital! While exact numbers will vary from region to region, health district to health district, local authority to local authority, the problem hardly looks overwhelming.

But the very smallness of the numbers involved, ironically, looks like bringing its own dangers. The danger now is not so much that children are being consigned wholesale to live in hospitals which cannot meet their needs, but that planners and providers of services may lose their sense of urgency about finding alternatives to the wards for the children already there. If we just wait for another five years, after all, statistics will show that the problem has been solved.

Yet what would that solution amount to? What it would mostly mean is that the children had reached their 16th birthday and so quietly disappeared from one set of statistics to form part of the adult hospital populations. The official figures show clearly enough how their chances of leaving hospital decrease with the length of time they have been there. In 1977, there were only 193 discharges of children aged 15 and under who had spent a year and more on the wards; in 1978, there were 217, and in 1979, only 136. And whatever the overall trends, children are still being admitted to live permanently in hospital.

Just how the numbers game can be played has been sharply shown by North West MIND. A year after its original study, it found that the number of children living in the region's hospitals had fallen from 133 to 101. But 29 of these children had simply disappeared into the adult statistics. Thirteen children had been admitted to the hospitals, some of them explicitly long-term; two had died and only three had been discharged.

What is happening behind the statistics in one region is likely to be happening in others—and sometimes, on a larger scale. The North West RHA, after all, has only 26 children in hospital in every 100,000 population aged 0-15, compared with, for instance, 73 in South West Thames.

So a breaking of the patterns becomes more, not less urgent, as the children in hospital get nearer that 16th birthday which will cut them off from the current official concern. It remains as urgent as it ever has, because the hospitals cannot provide the environment the children need.

The quality of hospital life

The Secretary of State's conclusion may be the clearest expression yet of official disquiet, but others have been reaching it for years. As early as 1951, Dr Brian Kirman of Fountain Hospital, the largest in the country to cater specifically for mentally handicapped children, was saying that "the decision to place a child in an institution on account of mental deficiency is almost never in the child's interest, but it may be in the interests of another child or that of the parents themselves". In the early 1960s a study by King, Raynes and Tizard pointed up the sharp contrasts between the life of children in hospitals and those, equally handicapped, in children's homes. In the first, it was the needs of the institution, not those of the children, which took precedence. And what that meant in practice was a dreary routine with scarcely a nod to individual attention or the essential components of home life at all.

If the contrasts between the two types of care were sharp then, they had barely been dented by the time Maureen Oswin made her devastating study of children living in mental handicap hospitals in 1978. The needs of children still took second place to the needs of the institution. As one nurse said, when the children were given an unexpected school holiday, "If the children weren't here, it would be OK, but we can't do our work when they're around".

The fundamental needs of the children for mothering and play were still ignored. While on average they got one hour of physical attention in every 10, they got only five minutes mothering. "All students start off with ideals and want to help the children to walk and play", said another nurse, "but they have to roll up their sleeves in the end and realise that they cannot waste time playing with the kids".

The claim of these wards to be offering "special care" to their multiply-handicapped inhabitants had its own horrible irony. For want of early physiotherapy, some children were growing up with appalling and permanent malformations. None was receiving speech therapy, although this could have helped some of them with their difficulties in eating. Some were in inappropriate wheelchairs; other aids were in short supply; there was inadequate assessment for sensory difficulties. Even elementary health care could be lacking. In five of the eight hospitals, children were suffering from "the poverty conditions of the nineteenth century" – chronic catarrh, runny noses, sore eyes, skin diseases, chronic recurring stomach upsets, bad teeth and worms.

The hospitals were not only, in short, failing to provide the special care and treatment the children needed; not only failing to provide them with what we would recognise as a home; they were making these severely handicapped children more handicapped than they needed to be. And in doing so, they were preparing them for what the chronically overworked and undersupported staff saw as their only possible future: a place on the adult wards.

The alternatives

There is nothing inevitable in these patterns. As early as the end of the 1950s, the late Jack Tizard was showing, in the Brooklands experiment, that there could be: another way. When the 16 Brooklands children arrived from their hospital ward to an ordinary house, they bore all the scars of institutional living: they were mostly unable to speak or play with others, bear frustrations or show preferences for different members of staff; they were liable to hit out, sometimes to bite, subject to violent rages. After a year in Brooklands, which offered the sort of education and care recommended by the Home Office for residential nurseries, they were a group who enjoyed playing, talked a fair amount among themselves, were affectionate, happy, interested in what they were doing and fond of the staff, as the staff were of them. "If the contrast sounds too good to be true," said Tizard, "it is because the child itself has exceeded our expectations."

The message of Brooklands was clear enough. Yet over the years it has become dulled. Alternatives to the hospital ward may have sprung up from time to time and place to place. But only the Wessex Regional Health Authority has offered a large scale and coherent plan to replace traditional hospital wards, with local units that cater for the children who need residential care in a defined population. By the end of 1980, there were 110 children living in six local units and another six units were planned for children still in traditional hospitals. Careful evaluation of the first units had shown that the children had progressed at least as well as those in traditional wards, with more, not less, access to specialist staff and greater contact with their families—and at a very comparable cost as well. Yet anywhere outside Wessex, the scheme remains experimental.

By the end of the 1970s, however, the Committee of Enquiry into Mental Handicap Nursing and Care (Jay Committee) was able to offer a model of care for the future in which no child at all would have to live in a mental handicap hospital. ' The model stresses the importance, for children, of living with a family; it stresses the importance of small groups in residential homes and of making those homes highly local to the people they serve — and so dispersed rather than clustered together; it stresses the need to draw generic health, social, housing and other provision into the service of mentally handicapped people, with specialist top-up only when the generic services can't provide what's needed.

For children who cannot live in their own homes, the Jay report proposed alternatives ranging from fostering to a place in an ordinary children's home, to one in a small, specialist home. While there was disagreement on the Committee itself about responsibility for services, about training for staff and about the extent of the need for NHS facilities to back local residential provision, about the model of care itself there was no dispute at all. And the Government has also accepted its outlines.

The Jay report's alternatives to hospital wards for children weren't picked out of the theoretical air, either. Each of them is already at work in different parts of the country. The question is not whether it is possible to offer them, but how soon, and to how many more children.

Blocks and confusions

Part of the answer to that depends on overcoming administrative and financial blocks to change. The need for cooperation and joint planning between health and social services authorities has been emphasised over and over again. Yet the North West MIND report shows clearly enough how far some authorities may have to go. Some of the social services departments in the region simply didn't know how many children from their area were in hospital or who they were. How many others across the country are in the same position?

The separate financing of health and local authority services hardly, as has also been said time and again, offers much incentive for them to get out of it. Local authorities which have found all their available money and energy stretched simply to offer the rudiments of support to parents with a mentally handicapped child at home-and sometimes not even that-have not shown themselves anxious to take on extra responsibilities. With only 2,200 places for mentally handicapped children in local authority and private and voluntary homes in 1977, and double that to find to meet 1991 targets, few local authorities have planned coherently to bring children out of hospital.

Those that have made the commitment, however, show what can be done even within existing constraints. The London Borough of Camden, for instance, knows of 200 mentally handicapped children under the age of 18 whose home is in the borough. Forty-three of these children are living away from their families; 18 are in private and voluntary homes (10 of them in Camden's care), 12 are in Camden's own homes and nine are in substitute families. Only four, in mid-1981, were in hospital, and only one of those placements was long-term. So it is possible to overcome administrative blocks. The DHSS consultative paper on transferring NHS resources to local authorities (see the section on Financing Change) could provide a powerful tool for overcoming the financial blocks as well. But there remain some underlying policy confusions that stand in the way of change, and these need to be tackled as well.

The first of these confusions has to do with where the proper responsibilities of health and local authorities for mentally handicapped children begin and end. *Better Services for the Mentally Handicapped* envisaged that the more severely handicapped would remain the responsibility of the health service, while the local authorities took care of the needs of the rest. But the division between these two groups has never been clear; there has been room for endless and often fruitless debate over exactly where individual children belong.

There has been a confusion within a confusion, too: it has never been clear exactly what sort of provision health authorities should be making for the children reckoned to be their responsibility. By the end of the 1970s, the list of possible alternatives to mental handicap hospital wards, garnered from official reports and guidances, included units which are:

- administered by mental handicap hospitals, but at the edge of their site, or
- off it altogether;
- on the site of general hospitals, attached to children's departments;
- off the site of general hospitals, attached to children's departments;
- off the site of general hospitals, attached to child psychiatry departments;
- on the site of general hospitals which also have units for mentally handicapped
- adults;
- in new district mental handicap hospitals;
- in specialist regional units.

But by 1981 several of these options had been closed. The latest guidance from the DHSS made it clear that health service provision for mentally handicapped children should be:

- separate from that for adults;
- off the site of a district general hospital;
- designed in a way that encourages a lifestyle as near as possible to that in an
- ordinary home;
- near to local schools, shops, parks, cinemas, churches and other community facilities and close to public transport.

And in a letter to the Guardian in July, 1981, Sir George Young underlined that these principles applied to accommodation for all mentally handicapped children. “For the children who are so severely handicapped or multiply handicapped that they require care in a health setting, provision should be made in small units and not in a large hospital.”

Perhaps it is time for health and local authorities, and voluntary organisations as well, to find their own way out of the confusions by agreeing a common philosophical base for what they offer. What makes the difference to mentally handicapped children living away from home, as the Brooklands experiment showed and subsequent research and experience has confirmed, is being treated as if they were children and not simply small mentally handicapped people. The point may seem obvious. But ever since the Curtis Committee on Child Care, in its 1946 report, deliberately excluded children with handicaps from its blueprint for child-care services, it has been obscured. The Court Committee's recognition that "severely mentally handicapped children have more in common with other children because of their childhood than they do with severely mentally handicapped adults because of their common disability" is the starting point for change.

A context for care

To end the use of mental handicap hospitals for children doesn't mean, above all, simply sending them home to their parents—any more than it means denying the support they request to those parents who would welcome them if they had it. It doesn't mean, either, concentrating on the needs of this small group of children to the exclusion of the very large majority of those with mental handicaps, who already live at home. If the demand for hospital places is to end, families must get the support they need—and that includes alternative short-term respite care to that now provided by the hospitals. For some children and some families, an end to the demand for a hospital place will mean another long-term alternative to the family home. To balance the effort to prevent admissions to hospital with the task of bringing children out may seem daunting. But it's important to remember what this is likely to mean at local level. The Guy's plan for a comprehensive district service, for instance, estimates that only four children in each neighbourhood (with a population of 20,000-25,000) will need somewhere to live away from their own home. The figure may vary from neighbourhood to neighbourhood; it will certainly vary between health districts. But it at least indicates that the problem should hardly be overwhelming.

This report doesn't go into the wider context of services to mentally handicapped children. Nor does it go into the broad picture of what they will need as they grow up if those who come out of hospital tomorrow are not to find themselves back there as young adults. There are already accounts of different sorts of support schemes for parents, and of the principles and issues in short-term care. There are documents on the shape of day services to mentally handicapped adults and on the overall patterns of residential care. There is new official guidance on the shape of all services. And there are blueprints for planning a comprehensive local service.

These documents form part of the essential context of this report, which is concerned with just one small aspect of creating that comprehensive local service. It is about offering mentally handicapped children now in hospital what all others who cannot live with their own families have been promised for over 30 years — a philosophy in action which recogmses that whatever their special needs may be, these will never be met until they are assured of affection, stability, an opportunity to develop and a place called home.

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Key Questions

Who are the children?

In the NHS, childhood ends at 16, which puts most of the children now in hospital uncomfortably near adulthood. At the end of 1978, the last year for which figures are available, the picture looked like this:

Children aged:
0 - 16
2 - 85
5 - 746
10-15 - 2094
TOTAL 2941

But should we be accepting 16 as the cut-off of concern? A hospital environment that cannot meet the needs of a vulnerable child is unlikely to meet the needs of a vulnerable adolescent. Local authorities are responsible for the children in their care until their nineteenth birthday. Children with mental handicaps also have a statutory right to education until this age.

If this broader definition of childhood is accepted, the number of children and young people who need an alternative to a place in hospital rises sharply. In 1980 in the North Western Region, for instance, there were 286 young people under 20 in hospital, of whom fewer than half (132) were under 16.

Whichever cut-off is chosen, many of the young people now in hospital have special needs. The OPCS survey for the Jay Committee (1976) showed that the inhabitants of children's wards in hospital had more severe difficulties than those in local authority children's homes. The picture looked like this:

Table 1

Children’s needs	Percentage in children’s wards	Percentage in children’s homes
Unable to walk alone	34	8
Unable to feed themselves	51	24
Unable to wash and dress themselves	79	44
Had behaviour problems	50	34
Doubly incontinent at least twice a week during the day	55	15
Doubly incontinent at least twice a week during the night	55	12
Blind (or partially sighted)	11	4
Deaf (and could not use a hearing aid)	5	3
Cerebral palsy	28	10
Heart condition	4	4
Respiratory illness	10	17
At least one epileptic fit during past month	18	8

Epileptic (including controlled)	44	18

In these units more than half of the residents were under 16. (From: Mental Handicap: Progress, Problems and Priorities, p.31)

These crude figures need to be interpreted, however, with some caution. All of us, after all, come into the world unable to walk, feed ourselves, wash or dress, and with severe problems of behaviour and incontinence; a severely mentally handicapped child may simply take longer to learn skills than others. Definitions of behaviour problems are notoriously tricky to pin down: what may look like a problem in one setting may not in another, and, in addition, the hospital environment has itself been shown to create behaviour disturbances.

It is important, too, to remember that no local service will have a huge concentration of children with special needs; in fact, the more local the service, the fewer children with such needs there will be. The Development Group for Guy's Health District offers a perspective on the question. Deliberately basing its calculations on the highest available estimates of prevalence of special needs, it came up with this picture for a neighbourhood of 20,000 - 25,000 people:

- Children with severe physical handicap - 3
- severe epilepsy or poor selfcare or incontinence - 3
- severely disturbed behaviour - 4
- no additional handicaps - 11

Clearly even the best of estimates can only be notional. But they do at least indicate what any truly local service can expect.

Whose responsibility?

The official DHSS position remains as it has essentially been over a decade: that some children will always need "continuous care in a health setting". But that brings us no nearer a definition of which children, with which particular needs, should be included in that category rather than being seen as able to live in settings provided or supervised by local authorities or voluntary agencies.

It is worth remembering that for every severely handicapped child now in hospital, there are two or three others just as severely handicapped living in their family homes. That doesn't mean that the children should be sent home from hospital, or even that the families are necessarily living without stress. But it does at least raise the question of whether many children who must have "continuous care in a health setting" actually exist.

Some people would say that they don't, and argue that if the fundamental need of all mentally handicapped children is for good child-care, whatever their degree of handicap, then that care should be provided within the overall pattern of what local authorities offer to other children who cannot live in their family homes, with specialist support as necessary.

Others might say that the demarcation dispute between health and local authorities has dragged on for far too long already, and wonder when a debate turns into an excuse for inaction. They might cite the DHSS's own findings on the Sheffield children's hostels to show that however carefully the divide between health and local authority provision is planned, the way that that provision is actually used may have little to do with the theory.

The Sheffield Development Project was set up by DHSS, in conjunction with Trent Regional Health Authority, to turn the 1971 White Paper Better Services for the Mentally Handicapped into action. It divided children into three groups:

- A, who because of additional physical handicaps or severe behaviour problems, needed the support of a full hospital service fairly close at hand;
- B, who require some more limited medical and nursing supervision;and
- C, who were seen as a local authority responsibility.

By March 1979, the first and obvious thing about the hostels for each of these groups was that they were grossly underused. Only 36 out of the 68 hospital places were being used-even though the original plans had been for 100. Only 37 of the52 provided by the local authority were used—and this even though children had been brought in from outside Sheffield and allowed to stay on after the age of 16. Nor was there any clear distinction between the degrees of handicap in the hospital and local authority hostels. Although all the local children who could not walk were in the 'A' hostels, the 'C' hostels also took in children with problems in walking. There was no difference between the different hostels in the number of children who had severe problems with vision or hearing. While one of the 'A' units was among the three who were unwilling to take children with severely disruptive behaviour, one of the 'C' hostels actually specialised in them, although their problems made them sound like candidates for 'A' care.

The moral of this particular tale seems to be two-fold. First, at a time of changing expectations and population, it's wiser for authorities to rent small, ordinary housing than invest in elaborately purpose-built hostels. And secondly, it's as well not to put too much store by theoretical divisions of children into health and local authority responsibility.

Whether such a division can usefully be made at all might become clearer when DHSS has completed its own evaluation of services to children in Hereford which starts in 1981. At the moment, however, it looks as if who eventually provides what for whom will depend less on theoretical criteria than on whether the NHS keeps the cash that is currently sustaining children in hospital or transfers it to local authorities.

And meanwhile, the examples in this report show clearly that health authorities, no less than local authorities, can offer children a home, just as they show that local authorities and voluntary agencies can offer a place in a foster home or small local home to children with very severe degrees of handicap. And they show too that in arguing the toss between health and local authorities, it is important not to forget the crucial role of housing departments.

How specialist a service?

This question arises from the one above and is no nearer a clear resolution. Some people argue that there is a need for highly specialised units for children with particular additional handicaps—especially those who are both deaf and blind or have severe problems of behaviour. Others argue that there is no evidence at all that such specialised units as do exist provide anything that a mixed unit can't. They argue that by taking children from a necessarily large catchment area, specialised units actually militate against their development and integration into their communities by separating them from their families and familiar contacts.

The Jay Committee summed up the arguments for and against highly specialist homes like this, before concluding that its model of care should allow for some homes whose catchment area would be a region or part of a region (without, however, referring particularly to children). Those who favoured separate more specialised short and long term accommodation for the most severely handicapped argued that:

a) The staff in the local homes would be more likely to accept the more severely handicapped and difficult residents and to try to help them if they knew that there was a back-up residential service available.
b) Unless specialised homes were planned from the outset with appropriate staffing levels and with staff who had the right kinds of skills and experience such homes would emerge spontaneously as dumps for the most difficult residents.
c) Without such specialised accommodation staff would be unlikely to develop the special skills required and new techniques for modifying socially unacceptable behaviour and stimulating unresponsive people would be unlikely to develop. The experience needed to meet special needs would be gained only through continuing contact with particular problems.
d) It would be possible, through transfer of a resident to such a unit, to modify his behaviour successfully so that he could then return and live successfully in his original home.

Against this it was argued that:

e) The availability of such back-up units would of itself encourage staff in the ordinary units to give up too easily when faced with a difficult resident and to pass the buck.
f) Moving a client from one home to another could actually create additional problems of adjustment for the handicapped person.
g) Grouping the most severely handicapped people together, even given an appropriate staffing level, was unworkable and would probably lead to low morale in these units.
h) Difficult behaviour which might emerge in one of the local homes might not do so in the specialised unit. Similarly, new behaviour learned in the specialised unit would not necessarily be carried back to the person's home.

(Reference: *Report of the Committee of Enquiry into Mental Handicap Nursing and Care*. p.51)

Certainly the experience of the Eastern Nebraska Community Office of Retardation with its home for children with very severe behaviour disorders was that what set out to be behaviour shaping turned into behaviour sharing. The staff found it hard to tolerate such a concentration of difficult behaviour. The unit was closed and all the children were found what the agency thought were far better, more individual places to live. Certainly, too, Maureen Oswin's diagnosis of professional depression among staff caring for multiply handicapped children raises questions not just about the ways in which management does or doesn't support staff, but about the strains of working with a group of children who are all very dependent.

The examples in this report don't offer any quick answers to the question of specialisation. But they do show that children with very differing needs can live and develop together. They don't, either, answer the currently debated question about what training staff should have to care for severely mentally handicapped children. But they do show that units which are run by nurses can provide high standards of child-care. They do show, too, that staff whose only training is in-service orientation can do the same for children whose handicaps may be very severe.

What other services?

To move children to a new residential setting hardly guarantees that they will get the help they need to develop. As some of the examples in this report show, it may be easier for a child to find a new home than a new school: clearly education authorities need to be brought into the equation of cooperation, as much as health, social services or housing authorities. As the examples show too, consultants in mental handicap or psychologists may have an important part to play—not as managers, but as consultants to individual children or groups.

Social workers may have an important job to do in helping families strengthen or re-find their links with their children. Community mental handicap nurses may also have a role. Individual children will have their own special and different needs. But the examples here confirm what the evaluation of the local Wessex hospital units has shown: it is likely to be far easier to find specialist help for a child in a community setting than to attract scarce professionals from their community base to distant, specialist institutions.

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The first step

“The first step is for health authorities to take steps now to identify children (who do not need specialised health care) and to consider ways and means of making other provision for them in consultation with their local authorities and voluntary bodies as appropriate.”
Patrick Jenkin, Secretary of State for Social Services, 10 December 1980.

“We should be aiming not only at getting the right setting and improving the quality of care, but at making sure that from the earliest stages in a child's development he is getting the training and remedial treatment he needs. Loving care is not enough. No child should through ignorance or neglect be left to develop anti-social behaviour or to fall into a greater state of dependence than his handicap warrants. Experience and research have shown that far more can be done than was thought possible 20 or even 10 years ago. The message is therefore not just alternative forms of care, but services that we can genuinely be satisfied are better.”
Sir George Young, Parliamentary Under-Secretary of State, 9 June 1981.

In 1970, there were 147 children under 16 living in Harperbury mental handicap hospital. By the beginning of 1981, there were 18. And the children's unit there was operating on a tenth of the places that the DHSS considers the norm for the population it serves.

The unit has achieved this dramatic reduction in numbers, for a start, by being clear what it is in business for. It is there not so much to provide continuous care in a health setting as to offer specialist treatment for only those children who, it believes, cannot find what they need elsewhere. There are not so many of them in the five London boroughs (seven health districts) the unit serves. Fewer than 60 children have come into it for other than strictly short-stay periods of treatment since 1970, and only six of them since the end of 1978.

This policy brings its own demands. The unit has worked very hard indeed, in co-operation with local authorities and voluntary organisations, to find alternatives for children who don't need what it provides—and, as crucially, to support them in their new homes. And it has worked, too, to prevent demand and need for admission among children who are in their own or alternative homes.

Not all the fall in numbers in the unit can be attributed to this policy. In the past decade, eleven children, all very frail, have died there—which is the number that would be expected in the size of population that Harperbury serves. Almost 50 young people have passed the great divide of their sixteenth birthday and moved to an adolescent ward—including two in the past year. But between August 1970 and March 1980, 89 children found an alternative place to live.

- 3 children went to other hospitals
- 8 children went to residential schools
- 46 children went to residential homes (private and voluntary)
- 21 children went to residential homes (local authority)
- 2 children went to foster homes
- 9 children went to their own family homes

Over the same period, six children came back to Harperbury—four from private and voluntary homes, one from a local authority home and one from a residential school. Two of them subsequently found another home.

As Dr Derek Ricks, the consultant in charge of the unit, sees it, the fundamental task in making this possible has been to build a network of goodwill, with a genuine commitment from the hospital to bring continuing support and back-up to the places where the children are now living, and a commitment from those places to work hard on their behalf. Finding the places, he says, is less of a problem than has been made out; the essential is that children are supported once there by people who have a real appreciation of their sometimes extremely complex needs.

The philosophy applies as much to children living in their own homes as to those inalternative ones. Dr Ricks himself spends by far the bulk of his working time outside the Harperbury unit, at the eight clinics he runs through its catchment district, and visiting alternative homes. The unit's senior registrar in mental handicap, paediatric registrar, full-time psychologist and senior physiotherapist can be called on to provide support; so can the head teacher at the neighbouring school for autistic children and the head of Harperbury's own unit for children who are deafand blind. Dr Ricks is adamant that the job of the Harperbury team is not to take over local services, but to support people looking after children—whether these are parents or care staff. The policy hasn't always been easy to get across; he has, on occasion been accused of abdicating responsibility when he has insisted that it is a local referring paediatrician, not himself, who should have medical responsibility for a child. But one measure of the policy's success is that it is very rare, now, for a child to be admitted to Harperbury as an emergency.

So who are the children who Dr Ricks sees as having a legitimate reason for coming to live in the unit? They are mostly between eight and 15 years old, and mostly at the top end of that age-group. The problems they bring with them have to do either with the severity and complexity of their multiple handicaps, or with the way they behave; about two-thirds of them come because their behaviour appears intolerable to those with whom they live. They may need the help that the unit's two and a half full-time physiotherapists and others can offer to, learn, for instance, to sit and balance, to eat unaided, to bear their weight on their feet. They may benefit from the environment that the neighbouring day-school for autistic children offers. Or they may bring a large question-mark to any offer of help yet devised.

In mid-1981, the group of children living in the unit was made up of six who are blind and deaf, eight whose multiple handicaps include autism and four whose behaviour is no less of a challenge for being outside that classification. Some of the children have been in the unit for four years or so, and Dr Ricks sees the assumption that all we need is more local resources as a gross oversimplification of their complex needs. He supports wholeheartedly the model of care proposed by the Jay Committee, of which he was a member. He agrees that ultimately it should be possible for the small local units it envisages to meet the needs of all the children who are in search of an alternative home. He knows from experience that the large majority of children whose behaviour is said to be intolerable can be greatly helped by finding ways for those around them to react differently to that behaviour and so meet their needs more effectively. But he also believes, as he said in his Note of Dissent to the Jay Report, that a viable local service depends on NHS backup of the sort that Harperbury tries to provide.

That back-up service, with its residential component, should, he says, do two things. First, it should offer specialist help to children with very complex problems not when they are approaching adolescence, but when they are very young—when physical difficulties can be better worked on, and when inattentive behaviour hasn't had the chance to develop into what is dubbed intolerable. And secondly, that service should try to understand, explain and then work to overcome behaviours which simply cannot be explained as a reaction to environment. There are not many children whose behaviours defy such understanding: Dr Ricks reckons that four of those currently in Harperbury fall into that category. But he is also determined that the depth of the challenge they pose to plans forcomprehensive local services should not be glossed over.

By mid-1981, there were plans to offer the components of the back-up service Dr Ricks envisages outside the grounds of Harperbury hospital itself. A large house was to be converted which should eventually have facilities for parents to come in for residential courses in helping their handicapped child as well as providing a home for the children who now must live on the unit's wards. There were discussions, too, with MENCAP about setting up a small unit specifically for the children whose behaviour baffles the best intentions of those who care for them.

Harperbury's experience over the past decade brings two clear lessons for other hospitals and local authority and voluntary services. The first is that it is more than possible to enable children now living in long-stay hospital wards to find an alternative home—if everyone concerned is fully committed to working together. The second is that if each child is really to be offered the best possible opportunity to develop in the best possible setting, there needs to be a constant attention to his or her often very complex and individual needs, which will involve different sorts of expertise.

The way this expertise is offered will vary. Some workers, for instance, would challenge the notion that children who are deaf and blind are best helped by living together with others who share their particular handicaps. Other workers would challenge the idea that we need a specialist NHS back-up residential unit which must necessarily draw children away from their own localities and family and other links. The Harperbury approach is one answer to one series of questions.

It is also one answer to another, which is critical to the coherent development of a service to mentally handicapped children: whether children with mental handicaps should be treated primarily as small mentally handicapped people or primarily as children with special and sometimes complex needs.

The Royal College of Psychiatrists maintains that the responsibility of the medical consultant in mental handicap should cover both adults and children; although it talks of cooperation with child psychiatrists and paediatricians, it is relatively clear that the consultant in mental handicap remains the most important person in the lives of many mentally handicapped children. The National Development Group has gone some way along this route, with its recommendation that Community Mental Handicap Teams should work both with adults and with children whose problems are severe.

Dr Ricks, however, works differently. He is, so far, the only consultant in the land who works exclusively with mentally handicapped children; he sees a major part of his job as supporting local paediatricians in their own responsibility to these children. His approach is nearer that of the Court committee on child health, which wanted to see District Handicap Teams that meet the needs of all children with handicaps, and wanted responsibility for providing supporting health services to those who are severely retarded to pass from consultants in mental handicap to paediatricians and child psychiatrists.

Whichever approach is adopted, Harperbury's lessons remain. It is possible to find a better place for the children now in long-stay hospital wards. And, as this one hospital's plans for the future show, an NHS contribution to residential care need not be synonymous with a place on a traditional mental handicap hospital campus.

Further information on Harperbury Children's Unit: Dr Derek Ricks, Harperbury Hospital, Harper Lane, Radlett, Hertfordshire WD7 9HQ.

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Adoption

"The trouble with Adam", a professional worker once told his mother, "is that he's got a mind of his own". Adam's mother thought that was one of the most awful statements she'd ever heard. "If Adam wants to do something", she says with some pride, "he'll do it".

Adam has wanted to do quite a lot since he came to live with Jean at the end of 1979 and became her adopted son early the next year. The staff in the mental handicap hospital where he was living when she first met him told her that he was unaware of his surroundings and wouldn't react to any change in them. "How untrue that was! The first time I took Adam out of the hospital he spent the day crying and throwing himself about the floor, banging his head and becoming very distressed. He would not eat or use the toilet. He would throw himself back and bang his head on the wall. I began to wonder if I was doing the right thing by taking Adam away from the only environment he had known. If I had continued to believe this Adam would not be with me now."

But she didn't and he is, coming up for his eighth birthday. He no longer goes into a tantrum if his food isn't put in front of him as soon as he's sat at table; Jean can now take him anywhere without trouble. He is beginning to turn his bottom-shuffle into a crawl. He's completely toilet-trained during the day. He doesn't spend a lot of his time, as he used to, drumming his feet and making a series of repetitive gestures. Instead, he shows a fair amount of interest in the toys that Jean and the occupational therapist at school have been working on in their search for the most stimulating activities for a child who can only see enough to make a small distinction between light and dark. And he and Jean spend a fair amount of time laughing together and cuddling each other, both evidently delighted to be doing it.

It wasn't easy for Jean to adopt Adam. Though she'd had no idea of adopting a handicapped child before she met him, the moment she first saw him creating chaos round a meal they shared, she knew that it was Adam she wanted. But the hospital he lived in was very unsure that a single parent could take on a child with so many handicaps. It was only after six months of regular visits to the hospital that Jean got to take Adam out at all.

Life hasn't been plain sailing since Adam arrived, either. There can be particular problems: he has already needed one operation on the shunt that controls his hydrocephalus. There are also more general difficulties, that any mother of a handicapped child would recognise. Jean knows that getting about will present increasing problems as Adam gets older if he doesn't learn to walk. He is very dependent on her; her original intention to go back to work as a nursery nurse is on ice at the moment. Constantly having to meet all Adam's basic needs isn't always easy, particularly if she isn't well herself.

Some things make the caring easier. There is the constant support of the agencythrough which Jean and Adam met. When she decided that she wanted to adopt him, a housing trust found her a ground floor flat. She belongs to a group for the mothers of children with handicaps. Adam is on the books of a special clinic at a teaching hospital in which she has confidence. His school, she says, is excellent, and cares for parents as well as children; she can call on its occupational therapist and physiotherapist for help. Her family and friends, who at first thought she'd taken leave of her senses, are now delighted by Adam and offer different help of their own. After a horrific start, when the manager of the local social security office had failed to get the social worker's message, and told Jean she simply couldn't just throw up her job and expect financial support, money has not been a particular problem. With social security and child benefit, topped up by mobility and attendance allowance, she's not, she says, complaining.

Complaining, in fact, looks like the last thing either Jean or Adam are doing. She knows that he needs special care and that children with handicaps often bringheartache to the people who love them. But, as she says, "they also bring love and joy into our lives. I thank God for the privilege of being able to love and care for a special child".

Jean and Adam met through Parents for Children, an adoption agency which works to place children with special needs who are in the care of local authorities in London and the Home Counties. Since it began, five years ago, Parents for Children has found homes for 50 children, 21 of them with mental handicaps and most of those younger children with Down's Syndrome; two of these children have come from hospitals.

What Parents for Children has shown is that the range of children who can find adoptive parents is just as wide as the range of people who can be those parents, once preconceptions about suitable children and families have been broken down. That's the first lesson, and it's beginning to get across. The agency finds that fewer babies with Down's Syndrome are now being referred to it, for instance, because local authorities themselves are finding adoptive parents for them.

Other lessons from Parents for Children's experience are no less important. The first is that age can be a greater handicap to a child's chances of finding a new home than any degree of disability, and that brings an urgency to the search for parents for a young child. In its fourth annual report, Parents for Children shows clearly enough what can happen to handicapped children if they are allowed to drift through years in care. "Even severely handicapped children can face a still greater disadvantage in respect of family placement—that of institutionalisation. When these children play 'Mothers and Fathers' they say 'Who will be night-staff?' and see no incongruity in it. They talk about wanting Mummies and Daddies, but we realise that their only experience of parents is of those who visit the children's Home, and perhaps they see little difference between parents and social workers or aunts and uncles who are all people who take them out and give them a treat, or come and spend time with them and make them feel a little special. They are not people who care for them night and day and share their lives, whom they see in night-clothes as well as day-clothes, and in all their moods, good and bad. So no wonder by age 14 or 15 there is little incentive to adapt when the idea is so foreign. We can see what they have missed and are missing, but we judge by standards that mean nothing to them, and yet they are the people we are asking to adapt."

If Parents for Children's experience brings a lesson about the way adoption agencies go about their job, it also brings one about finance. In general, the more severely handicapped an adopted child-as any child-the higher the financial benefits to which he or she will be entitled. But nevertheless, some families who are fostering children with handicaps simply cannot afford to adopt them, because they need the fostering allowances to balance the family budget. The 1975 Children Act has a provision, due to come into effect at the end of 1981, which enables adoption agencies to make payments to adopters under schemes approved by the Secretary of State. This provision could make all the difference between a secure family home and the inevitable lingering uncertainty about the future that comes with fostering for some handicapped children.

A third lesson from Parents for Children is one for hospitals and local authority social services departments. The agency can only work with children who are in local authority care. It was in 1972 that the Department of Health first issued a circular on children living in long-stay hospitals which reminded those hospitals that children who had lost all parental contact could be taken into care, and so assured some concern for their welfare from a child-care agency. A year later, while some hospitals had informed local authorities of children who were abandoned in hospital, others had not. How many children are still lost to local authorities in this way?

A fourth lesson is for anyone who provides supportive services to families with mentally handicapped children. Although adoptive parents will have special contact with adoption agencies for a while, more than this is likely to be needed. Parents for Children is committed to supporting its own families for as long as they want this. And their needs for other sorts of support will be just the same as those of any family with a handicapped child, as the years go by.

Further information on adoption for mentally handicapped children:
Parents for Children, 222 Camden High Street, London NW1
British Agencies for Adoption and Fostering Resource Exchange, 11 Southwark Street, London SE 1.

Fostering

When Jimmy comes down from his afternoon nap, he's a bit shy of this stranger sat talking to his foster-mother. But after he's had his drink, he runs off happily enough to put the cup in the kitchen sink as requested. It's not long before he's treating the world to his dazzling smile, making small chatty sounds and giving his toy car a test run over the visitor's knee.

Jimmy came into the world with a low birth-weight and arrived at his foster home as a baby with a diagnosis that included some spasticity and a query over his mental development; there have been times when it was wondered if he'd learn to walk. Now he's three and though his legs may need some attention, he walks well enough; he's making the sorts of sounds his foster-mother recognises from other children when they were nine months old; he understands, she says, a lot. She and her husband had no thought of taking a handicapped child for the whole of his childhood, her expertise being in short-term fostering of babies. But when Jimmy's mother decided that this is where he should stay, they were over the moon with delight at the thought of keeping him. The other children - aged 15, 13 and 11 - were as delighted. Now, as their mother says, "we just don't think of him not being here".

Jimmy now goes to a nursery two mornings a week—and though at first his foster-mother didn't much like the idea, because she didn't take him to put him out of the house, she now sees that he's learning from being with a group of children who aren't handicapped, as well as from the special attention that he and another three handicapped children get for part of each morning. He goes to a special clinic at a nearby teaching hospital every three months and his foster-mother has nothing but praise for the staff there; she knows she can take him in to people who know and care about him if ever she's worried, and that they will fix tests for his speech, hearing and anything else that needs attention between times. She's glad to know that her social worker is on the end of the phone—though she hasn't yet felt any need to call on her help. The £22 a week fostering allowance she gets at the moment is enough for Jimmy's needs.

Jimmy's handicaps worry her not, she says, at all. Her only concern is that he will go to an ordinary school and not a special one, and so grow up in the ordinary community of which her other children are a part. They add their determination that he'll learn to do as much as possible to her own. She wonders why so much fuss is made about children with handicaps. "You just talk to them as if they're normal", she says. "Well, they are, in their own way, aren't they?"

Jimmy is one of nine mentally handicapped children in the care of the London Borough of Camden who has found a foster home—and that represents a quarter of the total. The borough's general child-care policy is that as far as possible no child under teenage should live in a children's home rather than a foster home- and that policy applies to children with handicaps as much as any others.

Three factors help Camden bring them into its overall child-care approach. The first applies to all foster families in the borough: the housing department is committed to rehousing them if that will enable them to take a child. The other two factors are more special to children with handicaps. Camden has a full-time worker whose job it it is to find and support short-term as well as long-term families for mentally handicapped children. And the borough is very aware of the advantages of being able to call—as other London boroughs and indeed large cities can—on a galaxy of specialist medical and other talent to meet the special needs of individual children.

Short-term or respite fostering for mentally handicapped children who live in their family homes—or indeed, with foster parents—is now becoming a recognised part of the help that can be offered: at the latest count, there were at least 14 schemes across the country. But now social services departments and others are activelypromoting long-term fostering for mentally handicapped children and experience so far shows that children can come straight from a mental handicap hospital into a foster home.

Barnardo's North West division has been running a professional fostering project for children with mental and other handicaps for the past two years. In the first year, 6 children found new homes; by the end of summer 1981, the total should be 15.

The emphasis of the programme is on its professional content. The four fostering workers (who also are responsible for finding families for some children who are nothandicapped) work very much as the partners of foster parents rather than their bosses. The foster parents have seven evenings of training—on the philosophy of normalisation and child development rather than handicap specifically—and are expected to come to monthly meetings once they have their child. Barnardo's own clinical psychologist visits the families regularly to help them plan individual programmes for their child, and the agency is now finding that its first foster parents are themselves asking not just for specific discussions at the monthly meetings-on the management of epilepsy, for instance, or play—but for programmes which will help the children learn very specific skills. The foster families are paid £55 a week on top of the normal boarding-out allowances. This cost is met by the local authorities who are responsible for the children, while Barnardo's itself pays the salaries of its workers who place the children and offer regular support to the families.

Priority has been given to children who are at the moment living in Barnardo's own children's homes—and about a half of the children placed so far have had at least one spell in a mental handicap hospital. Many of them have severe and multiple handicaps, and their ages range from 4 to 17.

Experience so far has shown that the experts who doubted that children with severe handicaps could be placed should think again. There is certainly no shortage of people who show an initial interest in becoming foster parents—the first round of publicity for the scheme brought 260 inquiries and the second over 700. Though clearly many people dropped out once they realised what would be involved and Barnardo's itself has been very selective, that response at the least shows a huge store of goodwill towards handicapped children and a willingness to see them as part of the general community. Local authorities were, by mid-1981, beginning to get the message and contact Barnardo's with a view to finding foster homes for handicapped children in their care. Hospitals were showing very little interest in the scheme.

Leeds social services department, which has one of the best-established and most successful short-term fostering schemes in the country, has a closer relationship with one of the local mental handicap hospitals. Its plans to launch a long-term scheme specifically include five children who are currently living in Meanwood Park hospital among the 18 that it hopes to place within three years. The scheme is designed for children with severe mental and multiple handicaps. It will be administered by MENCAP and financed, for its initial three years, by a grant from DHSS. The social services department will provide a specialist worker who will be responsible for recruiting foster families, setting up a contract with them to meet the particular needs of the child, liaising with other agencies to meet his or her needs and generally working within the rules and customs of fostering. The foster parents, for their part, will generally live in the city, undertake to attend training sessions, reviews and group meetings and to carry out the agreed individual plans for each child. They will be paid at the same rate as families who participate in the short-term fostering scheme, on top of the regular boarding out allowance and any others to which the child may be entitled.

Coventry social services department is another which shows what can be offered to mentally handicapped children and their foster parents, given enthusiasm and commitment. Over the past 18 months, its four specialist social workers have found homes for 26 children—two of whom came straight from hospital. On experience so far, the workers see no reason to say that there are some children who can't, because of the severity or complexity of their handicaps, be fostered. The scheme offers initial training and regular monthly meetings during the school terms to the foster parents and respite care with a short-term foster family if they want this. The department will also pay for adaptations to their home-like a downstairs shower-if this is what the child needs; physiotherapists, occupational therapists and home teachers are available to add their expertise. The foster parents are paid on a sliding scale on top of the ordinary boarding out allowance; this extra starts at £15 a week for a child under four and increases according to age—but can be varied according to the child's special needs.

Further information on fostering mentally handicapped children:

- In Camden
  Lesley Campbell,Social Services Department, Willing House, Grays Inn Road, London WC 1.
- Through Barnardo's
  Liz Dodson, Barnardo's, 7 Lineside Close, Liverpool L 25 2UD
- In Leeds
  Malcolm May, Social Services Department, Selectapost 9, Merrion House, 110 Merrion Centre, Leeds LS2 8QA
- In Coventry
  Ann da Silva, Social Services Department, (Adoption and Fostering Unit), Council House, Coventry.

Ordinary children’s homes

Susie sits in her buggy, right at the centre of things. The care staff for her group of children are careful to acknowledge her presence as they move in and out, changing one small boy, keeping an eye on two others who bounce about. Susie may not be able to see what's going on, but she is part of it. When she starts to whimper, she gets picked up for a cuddle. Later, when the group of children goes out into the playground, she goes with them, sitting on a staff lap as they dash about.

Susie is two and lives in an ordinary children's home. St Margaret's is a great barn of a place, a reminder of child-care policy past, when it was used as a clearing house for children who came into care from all over North London. When the borough of Camden took it over, there were still about 60 children living here. As philosophies have changed, so have the uses to which the place is put, and by mid-1981 its function was due to change again. By then, only four children were living there, although there was still space for 16, in two groups; there were hopes that Susie would find a foster home. Nearly 30 other children, some of them with different handicaps, were coming to the building for day, and sometimes respite residential, care.

But for the past 20 years at least, the place has offered a home for children with different handicaps in among the others who have come to it. Bobby, Elizabeth and Mary—who we shall meet in Where to Next?—spent almost all their childhood here. Kate Lawrence, who is in charge of the home and has been here since the early 1960s, sees no difficulty in that. The handicapped children who have lived here,all, she is convinced, became more capable because they lived with children who didn't share their handicaps; there have never been so many handicapped children that their presence overwhelmed the needs of the others. Those children, she is convinced, too, gained from living with the handicapped ones; they learned to accept different disabilities as part of the normal world. And certainly the handicapped children who come now for day care seem an integral part of their group, sharing activities with the other children, getting small bits of help from them as needed.

That's not to say that the individual need that handicapped children may have for more specialised help has been ignored over the years. A teacher from the local special school, for instance, advises the care-staff on how best to stimulate Susie. Relationships with the teaching hospital where she had her cleft palate repaired remain excellent. At one time, a member of staff would take her there for physiotherapy; now a physiotherapist visits the home, so that all the care staff involved with her can learn how to handle those floppy limbs and stimulate her to use her standing frame. Over the years, too, local special clubs for handicapped children have played their part in helping different children to realise that they are not the only people in the world to have handicaps.

There have probably always been some children with mental handicaps living in ordinary children's homes, though a survey by the Campaign for Mentally Handicapped People in 1974 found that few social services departments were making a deliberate policy of offering this option for integration into their regular patterns of child care. How far this option could be taken up now will depend very much on the general movement of child-care in different localities. As fewer young children leave their family homes and as fostering is increasingly being sought for those who do, young mentally handicapped children might find themselves out of place among the older children who now take up so many of the available residential places; an older child, however, might not.

Barnardo's North West division has, throughout the 1970s, been pioneering in its deliberate policy of offering a home to children with often severe mental and multiple handicaps in its regular children's homes. The policy has been nothing but successful, for staff and children alike. But now, Barnardo's is finding, local authorities are tending to ask for places for fewer non-handicapped children; the integrated children's homes are becoming, by force of circumstance, more specialist. And, as we have seen, Barnardo's itself is concentrating increasingly on looking to fostering for the handicapped children in its homes. But its work over the past decade remains a heart-warming example of how children can teach their elders a thing or two about cooperation and mutual enjoyment, and about how a child-care system that wants to can find a place for children who have been excluded from its patterns for far too long.

Further information on integrated children's homes:

- In Camden
  Gerald Druce, Social Services Department, Willing House, Grays Inn Road, London WC 1
- Through Barnardo's
  Alan Kendall, Barnardo's, 7 Lineside Close, Liverpool L25 2UD

Specialist homes

In Skelmersdale

Michael is only too pleased to show you his bedroom with the spaceship wall-paper – and the four other bedrooms, the bathroom, the kitchen and the cupboards as well. Back in the living room, as he shows off for the visitors, the budgie, the dog, and the regular humans in his life, it's hard to believe that when he arrived here, just over two years ago, he was only just beginning to speak and called everyone nurse. It's not easy to believe, either, as he moves among the people and objects that so evidently make up home, that before he came here, the only home he had was an adult mental handicap hospital ward.

But that, although he was only six years old, was reckoned to be the only place that could contain him. His furious biting had already put one nurse in hospital and ensured his rejection from any children's setting on offer. In his first nine months here, tests showed his development to have rocketed by something like 18 months. His gains have been steady ever since.

Michael is one of the 10 children who live in the Barnardo's project for mentally handicapped children in Skelmersdale. And although his story may be the most dramatic among them, there isn't one who hasn't made considerable gains since they arrived. Some of them have particular problems of behaviour; others have physical handicaps as well. Seven of the 15 who have lived or are living in the project came from mental handicap hospitals; another would have gone to hospital had Skelmersdale not been there.

The project remains the most adventurous in the country in the way it turns residential care for mentally handicapped children into a real home. It started in 1976, with the then still experimental notion that severe mental and other handicaps need be no bar to offering a child a place in what the rest of us would recognise as an ordinary home. Barnardo's rented a couple of houses from Skelmersdale Development Corporation, knocked them together and set up house for six children.

The project grew from there to become the first example in this country of the core and duster model of residential services, pioneered in the United States by the Eastern Nebraska Community Office of Retardation. When Barnardo's first planned a duster of alternative living units scattered around the estates, into each of which two children from the original core house would move with two staff, people said it couldn't be done. The neighbours, they said, wouldn't accept it. Staff wouldn't work in them. Children like that couldn't live in the units, and even if they could they would surely come to grief on the roads. But between 1977 and 1979, four units opened, again rented from the always cooperative Development Corporation, and they have shown that the staff will and do and that the children can and haven't.

By mid-1981, the success of these very small units had pointed the way to the latest adaptation of the project. It became evident that even six children living together in the core house was too many to ensure the individual attention that the staff wanted to give and the children clearly wanted to get. So the first house was being re- adapted, to become a home for only two children. The notion of a core house was to disappear, and the project was to cater for only 10 children, instead of the 14 it was originally planned for. This had become possible partly because Barnardo's had increased its options through its specialist fostering scheme and partly because the children themselves had increased their own options by their developmental gains.
So some children were to be fostered; another was to go to a local authority home for severely mentally handicapped adults and others again were, it was hoped, on their way to their family homes.

In 1981, it cost about £220 a week to keep a child in the Skelmersdale project. They all went to the local school. The 10 regular and one relief staff members got their support from the project's director, from Barnardo's own clinical psychologist, who helped them plan programmes for each child, from the local GPs, health visitors and child development centre—and from their own husbands, wives and sometimes children. The capital cost of converting and furnishing the original core unit was about £15,000; the alternative living units have each cost a maximum of £3,500 to set up.

In Ashington

Since Peter came to live in the ordinary terraced house in Ashington which is now his home, he has begun to react far more to his surroundings. He makes more sounds and he laughs more often; he has made it clear that his favourite food is chicken in red wine. He has more and different surroundings to react to, as well. It's not often, after all, that a blind and profoundly multiply handicapped 14 year old who lives on a hospital ward gets the chance to go to the shops and the park which are now part of Peter's ordinary world.

Peter is one of five children, all with the sort of handicaps that are said to need continuing health care, who moved to this rented council house in Ashington from Northgate hospital early in 1981. The initiative for the move has been Northumberland Area Health Authority's, the first step in its pledge to bring all 15 children out of its Northgate ward to a home in their own home district. The next two houses are already being planned for.

It's only when you contrast this very ordinary first house with the hospital ward the children came from that the differences seem worth remarking-for a very ordinary, pleasantly-furnished house is what it is. Jennifer, who is 16 and has joined the local Girl Guides since she moved here, knows what that means. She, like the other children, goes back to Northgate to school, because the local special school, just down the road, hasn't been able to take them in. One day, the teacher was trying to get across the idea of every to Jennifer's class. One little boy she said, went home every weekend. Jennifer put in her own contribution: "I", she said, "go home every day".

The home has its contrasts with the hospital ward in staffing patterns as well as appearance. There is no cook and no cleaner; the eight care-staff take care of all that, just as they have a clear responsibility for ensuring that minor repairs are done by local tradesmen and that household goods are kept topped up out of the cash float provided. There are no special night-staff: four of the staff take it in turns to sleep in. The leader of the team is herself a nurse from Northgate, with experience in residential child-care; one other member of the team has considerable experience of working in the hospital. But the other six are local recruits, whose training came through the orientation course put on by Northgate when they were hired. They get their support from the local GP and health visitor, and from the community nursing officer, psychologists and social worker who are based at Northgate itself. The individual programme plan for each child is reviewed six-monthly by the care staff and the Northgate team. When you ask the staff what problems they count serious so far, they look at you in bewilderment. They can't, they say, think of any problems at all.

Julie, who is now nine, has become much more alert and trusting since she came to the Ashington house. She still takes a long time to feed, and she still has severe physical handicaps; but her gains, like those of the other children, are already noticeable. She had lived in Northgate since she was 18 months old; her mother thought it awful but knew that Julie had to go somewhere. When the idea of the move to Ashington was first put to her, she needed a lot of persuading – partly, she says, because it had never entered her head that

Julie could leave the hospital. Who would do the cooking, who would wash and clean, decide the menus and still have time for the children?

Now, Julie's mother is really pleased. She would, she says, have felt bitter if her daughter had been left behind. The nicest thing about the Ashington house? It's the smell of baking that hits you when you go in, she reckons—instead of the smell of disinfectant that greeted you on the hospital ward.

The Ashington House costs about £210 a week for each child. Capital costs have amounted to about £16,000.

In Winchester

When Emily arrived at the Old Rectory from a mental handicap hospital ward, the only movement she made was to turn her head from side to side. Her only communication was an occasional scream when she was picked up. That was in October, 1977. Six months later, she was feeding herself with a spoon. By the time she died, she was beginning to talk; there was some doubt about just how mentally handicapped she really was. She died not in hospital, but at home-in the Old Rectory. That, remembers Lyn Ballard, who is coordinator of the place, pleased her mother: "she said that Emily never seemed to be alive until she came here".

The Old Rectory is one of the Wessex Regional Health Authority's six locally based hospital units (LHBUs) for mentally handicapped children. Unlike some of them, it is not built for the purpose on an available hospital site: it is, as its name implies, an old rectory, just outside Winchester, protected from a busy main road by a lavishly-walled garden, its bedrooms large enough to offer space to more than one child, its living areas large enough to offer laundry room as well as office space and living and dining rooms.

And unlike some of the LHBUs, which have taken all the children who need a residential place from a catchment area of 100,000 total population, the Old Rectory takes only those children who are defined as a *health service responsibility*; it serves the Winchester and Central Hampshire Health District, whose population is 190,000. The first group of children who came here when it opened four years ago all came from mental handicap hospitals in Wessex or elsewhere; about three quarters of the nine were said to have severe behaviour disorders or to be hyperactive. The home was planned to offer, on the basis of prevalence figures, 16 places for long-term care and two for short-term; in the event, after searching its catchment area for suitable children, it finds that 13 permanent places and five respite, short-term ones fit the bill. It takes in any child who meets its criteria and is under 14. Since it opened, one child who had been in hospital has returned home, his behaviour made manageable there by his spell in the Old Rectory; another three children have returned home, with continued short-term care from the place; two children have died. In the four years that the Old Rectory has been open, not one child has been rejected as impossible to help outside a traditional hospital. By definition, the children who come to live at the Old Rectory—and most of them arrive after their eighth birthday—have considerable needs. Their behavioural, sensory or physical difficulties are severe enough for them to be dubbed a health service responsibility. In mid-1981, two of the children were blind, two were deaf and one couldn't hear and could see only a very little. Although all the children could bear their own weight, three of them couldn't walk at all independently and had to be walked up the stairs to their bedrooms. Some had epilepsy.

What the Old Rectory relies on to help the Children develop is a rigorous programme of skill-training. It estimates that there are no fewer than 1500 training sessions a week with the children, each of them recorded, each checked daily by Lyn Ballard and each checked again at the goal-planning sessions which involve all the staff. At first, it was thought enough to hold these sessions once a month. But the children have shown that they can learn quicker than that; now new goals, components of much larger ones, are generally set once a week, and each child will have a minimum of five goals to work towards.

The programme may sound forbidding, but it is so woven into the fabric of daily life rather than being presented in special training sessions that it becomes more a way of living for staff and children than a series of educational hurdles. It is the Old Rectory's proud boast that no child has yet failed to learn to eat independently. And that includes Jessica, who spent eight years in a mental handicap hospital: the staff there were confident that she would never learn this skill. But after eight days at the Old Rectory she was eating with a spoon and now uses a spoon and fork. She was also totally incontinent when she arrived- as were all the other children. She is now quite continent by day and by night—and so are half the others. A visiting psychiatrist may have been puzzled to hear the staff talk at one of their regular planning meetings, not about how the children were failing to learn, but how they were failing to teach. But the approach brings its results.

Few of the 16 care staff had any special training in the approach before they arrived at the Old Rectory. Lyn Ballard herself has considerable experience both as a mental handicap nurse and with using behavioural techniques; one of her deputies is also a mental handicap nurse. But the bulk of the staff get their training on the job.

They get their support from a local GP who used to do two sessions a week, but now looks in once, and from two paediatricians, one of whom has a regular session every three months. Visits from the District Management Team of senior nursing officer, clinical psychologist and psychiatrist are a recent innovation. Only half the children have been accepted by the local special school. A teacher comes in to teach the rest at home and the care staff work with her and the children.

The cost of keeping a child at the Old Rectory for a week is rather higher than the average LBHUs—and that worked out at about £165 in mid-1981. The reason the Old Rectory costs more has to do with it being fully staffed while not fully occupied; and perhaps with the amount of short-term care it offers which doesn't necessarily all show up in the books.

In Camden

When the young people who live in the large house on Shoot up Hill come back from school, they make straight for the kitchen-dining room that's very evidently the hub of the place. Alan makes the tea and pours it out; though only two of the young people can talk, there's a flow of communication through the mugs and biscuits. Two of the girls get into an argument; the staff defuse it by the sort of individual attention that has a lot more to do with friendship than it does with technique.

After tea, everyone finds something to do. Some are with one member of staff watching television in the living room; some are with another round a table at the end of the dining room, making paper collages while she chats with them and does some mending. Nick, who at 12 is one of the youngest members of the household, goes into the garden with a third to work off some energy on the trampoline before getting ready to go to his parents' home, as he has done every weekend since the staff established contact with them. James comes home by Underground from the college he goes to daily. Paul, who goes to the special care unit at the borough's Adult Training Centre and at 18 is the oldest of the group, comes in and gets himself some tea; there are no locked cupboards in this kitchen.

By 5.30, it's time to start preparing the evening meal which is the focus of the house's day. Though the cleaning lady helps make breakfast, there's no cook. Everyone participates in getting the other meals, whether directly, by helping with the shopping or by cheering on from the sidelines. There's a natural rhythm about the activities that has to do with the house being home.

The house is Camden's residential unit for mentally handicapped adolescents. In mid-1981, there were nine of them, with another due to come from a mental handicap hospital to take the tenth place. The ten care-staff are each attached to one particular young person, taking responsibility for contacts with their families and social workers, and for seeing to their clothes and personal needs. The staff also take it in turns to sleep in the house overnight; they can't remember a time when they had to wake the head of the unit or his deputy, who take turns to provide back-up.

The staff get their regular support from each other—at the weekly meetings where they discuss the individual young people and the life of the house. They also get the support of Dr Ricks from Harperbury hospital for particular difficulties—like, perhaps, the medication for the two young people who have epilepsy, or specific problems of behaviour. They find the six-weekly meeting with the Harperbury psychologist valuable: "we can talk", as James Lees, who runs the place, says, "in our own language".

In 1981, it cost an average of £240 a week for a place in one of Camden's homes for mentally handicapped people. That compares with £305 a week for a place in one of its children's homes, or £400 in a community home with education.

In general

These four examples raise some questions about the shape of special residential provision for mentally handicapped children-and offer some answers as well. Some of these are organisational: they have to do with the broader context of services of which the home is a part, with who provides the service and for which children. Others have to do with the context in which the children live: their contact with their family and neighbours and the general and special resources of their local community. Others again have to do with the training and support of staff.

The three statutory authorities all see their homes as part of a wider plan for services to mentally handicapped children and their families-whether at health district/borough, area health authority or regional level. Camden (which currently covers two health districts) sees its home as a component in its general child-care service, which includes support to families, foster care and residential services to adolescents. Northumberland AHA sees the Ashington house as one component in a general plan for better services to mentally handicapped people and their families, which starts with improved prevention and moves through family support and early intervention to a highly dispersed series of small residential units. As far as children are concerned, the immediate aim is to bring all those for whom Northumberland is responsible out of mental handicap hospitals. If other AH As which use those hospitals—both of which are in the Northumberland area—follow its lead, the children's wards should be closed by 1988. The Old Rectory is part of the Wessex RHA plan to continue to provide the locally-based hospital units which will eventually replace the traditional hospitals in their present form; already 110 children live in these units and there are plans for six more for different parts of the region.

How should plans be translated into practice? Much has been written in recent years about defining clear geographical areas and meeting the needs of their populations within them, through services that are truly local. But how local is local, and does the geographical principle matter when plans are being made to bring children out of traditional mental handicap hospitals? Calderstones hospital in Lancashire, for example, had in mid-1981 an ambitious plan to empty its children's unit of some children by acquiring ordinary housing as and where it could throughout its catchment area, rather than by working out the place of origin of each child and planning accordingly.

Both Wessex and Northumberland base their plans, by contrast, strictly on the geographical principle and the experience of years suggests that they are right to do so. Most of the problems the large mental handicap hospitals now present are the result of decades of concentrating mentally handicapped children and adults out of their own areas, and they and the planners are living with the vicious circle that that has created. Local services have become insensitive to the needs of mentally handicapped people because for so long so many of those people have not been there to press those needs. Their quality of life has suffered from the loss of contact with family and familiar places. The Wessex research on its locally based hospital units shows, how a service which is firmly based on geographical catchment areas can avoid the problems of concentration, draw on local services to meet the needs of the people for whom it provides and establish stronger contact between mentally handicapped children and their families. The experience of the Ashington house, which is very clearly for children whose families live in that area, has already shown that, with sensitive social work support, families and their children can begin to come closer together.

The Ashington house and the Old Rectory both show, too, a further advantage of a service that is sure about its boundaries—which is that it cuts through at least some of the questions about which children can and can't live where. The Northumberland and Wessex plans are both firmly based on the principle that local homes must serve all children dubbed health service responsibility who need residential care in their population. Neither the Ashington house nor the Old Rectory have found any need to throw that central principle out of the window.

If the geographical principle is important, how large should each planning area be? The answer will clearly have implications for the number of children to be served, and raises its own question about how. The Northumberland plan is based on populations of 60,000 and envisages housing with between three and five places within each. The Wessex plan is based on much larger populations, of 100,000, if all children who need residential care are to be offered a place, or more if it is only children for whom the health service is responsible: the Old Rectory serves a population of 190,000, in a single house for 13 children at the moment.

Does the size of the residential unit matter? Commonsense and experience suggest that it matters very much. The staff of the Old Rectory find that the number and variety of needs of the children in the house present them with no problems of providing programmes; but they say that fewer children would have more opportunity to participate in the life of the house. Large establishments usually demand their quota of cooks and cleaners. The Ashington house, the Skelmersdale houses and Shoot up Hill all show the enormous advantages to be gained by being small enough to abolish these special roles. It was the children in the Skelmersdale project who made it clear that even a group of six could offer them less of what they needed than a group of two.

The Skelmersdale project shows, too, that whatever the size of the geographical area to be served, there is no rule at all which says that all residential places for that area must be lumped together. It could have created a single home for 10 children; instead, it has shown that a residential service can keep its coherence and at the same time be very dispersed indeed. The evolution of the project raises its own question about the core and duster model which is slowly beginning to trickle into planning documents. Is the core necessary at all—or is it necessary only to get a local project off the ground? After six years, Barnardo's has found that it can run the Skelmersdale scheme without it. Is it possible, given a similar experience over longer than that and with many more schemes in the Eastern Nebraska Community Office of Retardation, to envisage a highly dispersed local service which has no core house, but only a core of coherent management around which the services can cluster?

The more dispersed a service, commonsense says, the more readily local community services will adapt to meet the needs of the few children it serves. Skelmersdale and Ashington both show the central place of housing authorities in the development of those services. Ashington and the Old Rectory both show—in a negative rather than a positive way—the central importance of bringing local education authorities into any plan for a residential unit and winning their cooperation. For the Ashington children to have to travel back to school in Northgate when there is a special school just down the road from their home is a serious limitation on their opportunities to make new contacts locally and become part of at least one section of their home population. For half the Old Rectory children to have their schooling at home makes special demands on staff to create opportunities for them to join in at least some school opportunities and to get out of those familiar surroundings.

A house to live in and a school to go to are needs that all children share. What about special services? The experience of all four homes is that these services can be provided from local resources—and although some of these are at the moment based in mental handicap hospitals, there is nothing to say they need be in future. The experience of all four homes, too, shows that it's easy to get over-excited about the medical needs of children with mental handicaps, even to the extent of saying that they must be under constant medical supervision. The examples show that some of the children will have special medical needs from time to time. But as far as everyday life goes, the key doctor in their lives is not a specialist but a good GP.

If specialists of different sorts may have less of a continuing role in the children's lives than has sometimes been claimed, they may have more of a role in supporting staff than has sometimes been realised. Each of the four examples shows how important specialist expertise can be to enable staff to do their own job. Each of them suggests, too, that debate about what this contribution may be could be a sight more fruitful than debate about the training of care-staff. Although the heads of all four units have either a nursing qualification and long experience, or the long experience without the qualification, none of the units has sought out highly-trained care staff. The experience of both the Ashington and Skelmersdale projects, in fact, shows that one of the most important qualifications for staff may be that they live highly locally to the home – not just because of the flexibility this brings to the hours and way they work, but because they bring their own networks of family and friends to build a bridge between the children and their community.

Finally, a lesson from Skelmersdale. No one knows how many or which mentally handicapped children will need residential services in future. Even some of those now in hospital may go directly into a foster home. The future demand for residential places will depend on factors as global as general population trends and shifts and as specific as the development of services to families, adoption and fostering. What's needed, then, is a residential service which is highly flexible to the changing needs not just of individual children who come to it now but of others who may or may not in future.

The Skelmersdale project has shown that it is possible to offer a residential service which far from locking children, now and in the future, into its bricks and mortar, rejoices in their development and growing ability to find new options. One moral of the Skelmersdale tale is that it's a sight easier to do that rejoicing if huge sums of capital haven't been tied up in creating today's best alternative. The start of a flexible, creative residential service for mentally handicapped children coming out of hospital wards looks like a small, rented house in an ordinary street.

Further information on special residential homes:

- In Skelmersdale
  Alan Kendall, Barnardo's, 7 Lineside Close, Liverpool 25
- In Northumberland
  Vince Gorman, Northgate Hospital, Morpeth, Northumberland
- In Wessex
  Catherine Swann, Development Division, Wessex Regional Health Authority, Highcroft, Romsey Road, Winchester S022 5DH
- In Camden
  Gerald Druce, Social Services Department, Willing House, Grays Inn Road, London WC1.

Special treatment units

There is a girl, now 15, who has defeated the best endeavours of the mental handicap hospital in which she lives. Her behaviour is said to be so violent that there can be no question of her living with others of her own age. It is so violent, in fact, that there can be no question of her remaining in the hospital at all, because neither its buildings nor its staff are geared to cope with such behaviour, let alone begin to meet her needs.

By mid-1981, that girl was on her way to Beech Tree House, an experimental unit attached to Meldreth Manor, a boarding school run by the Spastics Society for children who have both cerebral palsy and severe mental handicaps. The unit started in 1977, when it had become clear that some children were being excluded from Meldreth because of the severity of their behaviour problems. Since then, as Malcolm Jones, the psychologist who directs it, says, it has turned away a lot of children because they were not difficult enough, but not yet any because they were too difficult.

Beech Tree House has places for nine children. Some of the 20 who have been to it since it began have come from Meldreth Manor itself; three have come from hospital; most have come from their own homes, brought by parents united by their tenacity in seeking and securing the help that the unit can offer. The problems that bring a child to Beech Tree vary, for, as an experimental unit, it has tried to balance not just the needs of the group and of families, but its own needs to work with as wide a range of difficulties as possible. So some of the children have been extremely aggressive to themselves or others; some have had an ability to keep moving long after those around them are worn out; some have screamed for hours on end. Whatever their particular problems, what unites them is that their behaviour had become intolerable elsewhere.

Beech Tree works from the hypothesis that their extremes of behaviour need not be any inevitable part of their handicap, but may instead be an understandable reaction to the environment in which they find themselves. So when George, for instance, arrived at the unit from a mental handicap hospital, he had few skills; he would often scream and beat his face. The behaviour might seem incomprehensible. But in a crowded, noisy ward it might have been George's only way to get the attention he sought.

So Beech Tree sees it as its job to offer children other methods of coping to the ones which are ultimately so destructive to themselves and others. Its highly structured behaviour modification approach is used to teach the children communication, toilet training, attention training and self-help skills and to substitute more useful behaviours for the ones they come with. Work goes on throughout the life of the unit, individually and in groups inside and outside the regular classroom.

The programmes are carried out by seven full-time residential therapists and a full-time teacher in addition to Malcolm Jones himself and his deputy, who is a teacher too; each member of staff takes turns to do all the work around the unit-the teachers will help children get up, the residential therapists will do a spell in the classroom. And the parents of the children are critically involved in the programmes, for the whole aim of the place is not to teach the children tricks but to enable them to learn behaviours which they can use once they leave. All the parents have agreed, as a condition of their child coming to Beech Tree, to its staff visiting them at home and staying with them and their child if necessary; all of them are expected to come and work at the unit, if possible for two weekends during each school term.

Whatever the reasons for the children's behaviours, the Beech Tree approach brings its results. Eight of the first 10 children to move through the unit-where the average length of stay is less than two years—have been able to return to Meldreth; another has been able to go to a weekly boarding hostel attached to a special school for mentally handicapped children; the tenth died. George now has some sign language to indicate his wants, and will lead staff to other things he needs; he clearly enjoys exploring the possibilities offered by sign language. Patricia, who when she arrived would get up no fewer—at one count—than 81 times in the night and exhaust her family by insisting on their presence with her throughout, now sleeps through and can tolerate bedding. Philip has now reached the stage where he can go to the ordinary local primary school for half a day each week. At nearly £7500 for a 38-week year for each child, Beech Tree may be the sort of investment some children need.

It also re-opens all the questions about what place there should be for such very highly specialist units in any future service to mentally handicapped children. Does every region need some provision of this sort? Beech Tree, which has a national catchment area, cannot answer the question about how many children really cannot, without a spell of highly specialist treatment, live in their own localities. Local experience suggests that there are few: there were only four children in mental handicap hospitals from the London borough of Camden, for instance, in mid-1981. But that is not to say that their future must be there, and it is not to say anything, either, about the needs of the children who will be born in the borough in future. Must what Beech Tree offers be provided in a residential service? Malcolm Jones is hoping that when the unit ends its experimental life in 1983, its approach can be tested in a community-based service, largely non-residential, with only five back-up beds.

Can other, more local residential homes draw on Beech Tree's approach to increase their own expertise in helping children with extremely difficult behaviour? Should the NHS be offering what this experimental educational unit has done, as part of its own provision?

The questions can be multiplied, and the best that can be offered at the moment, perhaps, is not hypothetical answers but continuing practical efforts to meet the needs of each child. The Eastern Nebraska Community Office of Retardation has, on occasion, set up units in ordinary housing which consist of one mentally handicapped person with two members of staff—if that is the only way that that person can remain in their own community. Are we prepared to go as far as that?

Further information about Beech Tree House:
Malcolm Jones, Beech Tree House, Meldreth Manor School, Meldreth, Nr. Royston, Herts, SG8 6LG

What next?

Bobby, Elizabeth and Mary come home from school in high good humour. Bobby goes off with Derek-who with Mr and Mrs Smith, his parents, shares the house-to play records in his bedroom. Elizabeth roots round in the kitchen for a sandwich before joining them. Mary stays to exchange the day's news with Mrs Smith. When Bobby returns, he offers the tour of the house with some pride. Does he like it? Yes, he says. As much as the children's home? Better, he says; less noise here, less bossiness.

Until 1981, Bobby, Elizabeth and Mary, who are now 16, 17 and 15, lived at St Margarets, the Camden children's home in which they had grown up together since babyhood. Now they share their own house with the Smiths, whose 18-year- old son Derek is also mentally handicapped. And that way of putting it is exact, for the arrangement amounts to family placement stood on its head. The house is held for the three young people by the social services department, and they will become the tenants when they are of age. Whatever the Smiths decide to do in future, the young people will remain in their own home until they decide to leave.

The idea of this arrangement came from Parents for Children, which had been trying to find adoptive families for the two girls. After two years, it became clear that a regular family was not the best answer for them. The girls, after a lifetime in care, had no concept of what family life meant; prospective adoptive parents found it impossible to adjust to young people with quite considerable handicaps overlaid by so many years of institutional living.

But what also became clear while Parents for Children was working with the girls was that they already had a family, and that that family consisted of each other and Bobby. It became clear that what they really wanted was to stay together. So the agency suggested that Camden find a way to make this possible—a way that offered both security and the help from able tenants that they would need into the forseeable future.

Two strands of Camden's general child-care policy made the eventual solution possible. The first was the commitment of the housing department to rehouse families if this meant they could take in foster children; the second was the same department's commitment to providing housing for young people who had grown up in and were leaving the council's care. So the house was found and an allowance of £70 a week made for each of the children; the Smiths were given a guarantee that they would be rehoused if ever they wanted to move.

So far, there are certainly no signs at all of that. All Mrs Smith wonders is why she didn't do something like this years ago. Her own son has progressed enormously, she reckons, since he came to live with the others. She talks of plans for Bobby, Elizabeth and Mary to go to college or Adult Training Centre. It sounds as if they have found a security for their future.

Most children now in mental handicap hospitals are approaching their adolescence, or already in it. All planning for mentally handicapped children must take account of the fact that children grow up. But planning for this particular group needs to focus on it even more sharply, if they are not to fall into the terrible irony of returning to the very hospital that people have worked so hard to get them out of, after only a few years.

So planning for these children now needs to take account of how long they can stay at school and what further education is available for them. It needs to take account of the availability of ATC places, sometimes in special care units. It needs to take account of the availability of adult residential services—or perhaps to look rather differently at the whole concept of what a residential service could provide.

In the past, it has usually been assumed that there are two distinct sets of residential services—one for children and one for adults. The notion may be neat for planners; it's less clear that it is necessarily comfortable for the mentally handicapped people who must live with it. Camden's solution for Bobby, Elizabeth and Mary is one example of what can be done if people's feelings are put before their categorisation. Its policy that Shoot up Hill will be home for the young people who live there for as long as they want to stay echoes the same sort of thinking.

That thinking is spreading. The original plan for Northumberland AHA's Ashington house was that the children should move out of it when they reached adulthood, to make way for other children. Now, it is seen as their home for life, or until something better turns up-and in the recognition that that may not be until well into their adulthood.

Whatever the solution reached by individual schemes and for individual young people, the planning clearly can't be left to look after itself. The Wessex locally- based hospital units offer one example of what can happen if planning of services for children and adults isn't carefully synchronised. The local units have brought children out of traditional hospitals to offer them a quality of life which has been monitored and evaluated and cherished in a way which is without parallel in the country. The units have more than proved their point. But what has happened to the young people who have lived in them as children? Over the years, there have been five moves to other LHBUs, all among young people of 16 or older. There have been 13 moves to other residential settings, seven of them among children under 12. There have been 35 moves to private households, 22 of them among children under 12, eight among children aged 12 to 16 and five among young people over that age. But over the years, about half the young people who have lived in the units have gone back to traditional hospitals, most of them at the age of 16. And all but one of those 55 young people are still there.

Further information on housing for young people in Camden:
Ken Dixon, Social Services Department, Willing House, Gray's Inn Road, London WC1

What about Jane?

Jane is now 13 years old and lives in a children's ward in a large mental handicap hospital. She goes regularly to school and is beginning to show some small gains; she is starting to acquire some self-help skills to replace some of her repetitive and ritual behaviours; her attention span is getting a bit longer. According to her consultant, the ward staff are fond of her; they find her unpredictable behaviour no insurmountable problem. She seems to respond to the space she is given. Her consultant calls what she's offered compassionate containing.

Two children's homes have tried, briefly, to offer her more than that. She went to the first, an integrated home for children with handicaps as well as those without them, when she was about six. Her consultant reckons that that home could have contained her. The other children were certainly wary of her, but when he talked to them he realised that they were learning to take precautions. One small child like Jane, he reckons, can live in a group of others whose ages and abilities are mixed.

The head of the home remembers Jane's stay rather differently. She totally wrecked the group she lived with, she says—not just its furniture and toys, but its emotional stability. In the end, one member of staff was with her, and her alone, all the time. But the staff could only do this for a couple of hours at a stretch. The situation became impossible. Back to hospital for Jane.

Some years later, she spent a few months at another children's home—this time, a specialist one for children with mental handicaps. The staff there remember her stay ruefully. They say she was aggressive and unpredictable beyond the bounds of tolerance. She needed someone with her the whole time; if left alone, she would run away. The other children were terrified of her; they would leave the room whenever she was in it; the whole life of the group was destroyed. Eventually, Jane was given a single room whose windows were boarded, whose furniture dwindled to a mattress and a blanket and whose door was locked at night. The situation became impossible. Back to hospital for Jane.

Her consultant remembers that stay, too. Looking back, he reckons that the staff in the home weren't offered enough consistent support; they were left to cope too much in isolation. He hopes that his unit has now learnt enough for that not to happen again.

But will Jane get a chance to prove it? She remains in hospital and the plans for her future are uncertain. No one can predict how much her behaviour may change; no one seems to know how to help the process along; no one knows how large and strong she may grow.

Very few children present the degree of challenge that Jane does. But what about the ones who do? What about Jane's right to be offered more than compassionate containing?

Financing change

The first thing to say about financing a new service for the mentally handicapped children and young people who now live in long-stay hospitals is that it doesn't necessarily cost more to provide a good service than it does to provide one which cannot meet their needs. It may even cost less.

Any exact comparison between locally-based options and hospital wards remains elusive. The DHSS review Progress, Problems and Priorities picked its way through figures for 1977/8 to show that it probably isn't worth searching for. Research from Wessex has shown that the costs of locally-based hospital units are highly competitive with those of traditional hospitals. But that was comparing the hospital service with only one of the local options: the large residential home. Fostering, for instance, costs a lot less than residential care. When the range of possible local options is compared with what the children are offered now, the financial picture begins to look almost rosy.

It might look different, too, if we started comparing like with like. In all the discussions of relative costs, that has rarely happened. Perhaps it is time to start more often comparing the costs of alternatives for mentally handicapped children in hospital not with what they get now but with what is offered to other children who cannot live with their own families. A society that shells out £650 or more a week for an observation and assessment unit of unproven value, or thousands of pound$,a year on places in community homes which, whatever else they do, don't fulfil their primary aim of reducing juvenile crime, can hardly, perhaps, cavil at the sums involved in providing services for mentally handicapped children whose value to them has been proven. Perhaps before we look too closely at the budget books, we should look again at the place of mentally handicapped children in our hierarchy of worth.

If the problem is less an overall shortage of resources, than one of resources that are in the wrong place, how are they to be transferred from where we don't want them to be to where we do?

Transfer within authorities

Northumberland's plans for closing its ward at Northgate hospital and replacing it with small, rented accommodation give one idea of how relatively painlessly this transfer can be achieved.

The £55,000 or so revenue costs for the Ashington house have been met by a special allocation from the Regional Health Authority; the £16,000 capital costs were met by the AHA. The first sum will be needed into the future; the second clearly will not.

This special allocation has enabled the service to get over the hump of setting up new provision while maintaining the old. The running costs of the next two houses will be met entirely by closing the Northumberland ward at Northgate.

NORTHUMBERLAND AREA HEALTH AUTHORITY:
Robin Hood, Villa 15, Northgate Hospital — Estimated Revenue Costs

Here are the sums for the project, with the figures for the Ashington house based on full occupancy and those for the hospital ward based on the 15 places it provided before the Ashington children moved out.

Table 2

Ward Based Staff	WTE	Estimated Cost in 1981/82 in GBP
CHARGE NURSE	2	19360
STAFF NURSE	1	6837
NURSING ASSISTANTS (including 3 on nights)	8.5	45622
STUDENT NURSING	5	25093
DOMESTICS	3	13229
Total staff expenditure	19.5	110141
Other Expenditure		
Identifiable Transferable Code		
Heat and Light		4819
Cleaning Materials		419
Holidays/Clothing/Pocket Money		4290
Nurses Clothing Allowance		500
Engineering Maintenance		766
Total other expenditure		10794
Total overall expenditure		120935
National remaining costs attributable to 15/678 beds		30, 673
Total cost of running service		£151,608

Number of children : 5
Cost per child per week : approx. £194

NORTHUMBERLAND AREA HEALTH AUTHORITY

224 Alexandra Road, Ashington — Estimated Revenue Consequences

Table 3

Staff	WTE	Estimated cost in 1981/82
Charge Nurse II	1.00	8,517
Staff Nurse	1.00	6,837
Nursing assistants	6.00	29,989
Sleeping in allowance for 4 staff		700
Total staff costs		46,043
Other expenditure		
Rent and rates		890
Heat and light		690
Provisions		4,200
Furniture and equipment maintenance		600
Telephone		80
Cleaning materials		110
Transport		630
Building maintenance		290
Holidays		220
Clothing		880
Pocket money		330
Total other expenditure		8,920
Total overall expenditure		£54,963
Capital costs incurred 1980-81		
Adaptations		8,550
Furnishing/equipment		7,400
Total		£15,950

Number of children : 5
Cost per child per week : approx. £211

Transfer between authorities: joint finance

Allocations for joint finance have risen from £16.4 million when the scheme was first introduced in 1976/7 to £68.5m in 1981/2; a further increase to £71m is planned for 1982/3 (November 1980 prices). About a third of the money available has gone to mentally handicapped people.

Some examples of how it has been used in ways that are more or less directly relevant to bringing mentally handicapped children out of hospital:

- In Camden: Joint finance has been used to pay for a specialist worker who is responsible for developing the short-term respite fostering scheme for mentally handicapped children and finding and supporting long-term foster homes for these children. It has also been used to pay for two members of the borough's peripatetic care team, who have supported parents with a mentally handicapped child at home.

  Although both these schemes may seem more relevant to preventing the admission of children to long-term residential care than to bringing mentally handicapped children out of hospital, they are clearly part of the overall strategy that is needed to end the use of mental handicap hospital wards for either long or short-term care.
- In Leeds: Joint finance is being made available specifically to help bring children out of a mental handicap hospital into foster homes.
- In Islington: Joint finance has been used to create a local home for very dependent children who would otherwise be classified as a health service responsibility. It has also been used to create a short-term care home specifically for children whose behaviour presents such difficulties that if ever their parents could no longer cope they would almost certainly be classified under the same rubric.

Useful though joint financing is, it is hardly a whole answer to the problems of transferring resources between authorities. Although revenue costs can now be met by the NHS to a tapering degree over seven years and longer with the approval of the Secretary of State, local authorities in the present financial climate are clearly reluctant to take on many schemes which will have future financial implications for them. In addition, joint financing is a complex business and likely to get more so where the new health and social services boundaries don't coincide. It doesn't take in education and housing—though these may be critically involved in any scheme to bring mentally handicapped children out of hospital. It may, however, involve a voluntary organisation if that organisation has the backing of a local authority that costs will be met at the end of the period of tapering.

A survey into what AHAs felt about joint financing by the National Association of Health Authorities, in May 1981, showed that whatever its limitations, only one AHA (of the 60% who responded) was against continuing it. But only a third wanted to see a continuing increase on the allocation—unless current constraints on local authorities were eased, when the proportion was 44%. Three quarters of the AHAs which responded saw a case for two or more agencies sharing long term financial responsibility for some schemes, including those where the statutory position about who should be doing what was not clear—among them, schemes for mentally handicapped people.

Transfer between authorities: the future

In July 1981, the DHSS produced Care in the Community: a consultative document on moving resources for care in England. This makes some very far-reaching suggestions about the way in which funds could in future be transferred from the NHS to social services authorities, which are of quite critical importance not just to children with mental handicaps now living in hospital, but to very many other mentally handicapped people as well—including the 15,000 the DHSS reckons could leave hospital tomorrow if they had somewhere to go.

The document suggests four main ways of helping people who should not be in hospital to leave for more appropriate community services. None of these suggestions is mutually exclusive and all of them bring the possibility of voluntary agencies acting on behalf of local authorities.

The suggestions:

- removing the barriers to local arrangements for transferring people and resources from the NHS to social services departments;
- promoting closer cooperation between health and local authorities and advancing joint planning;
- transferring NHS funds centrally to social services departments;
- concentrating responsibility for a client group on a single agency.

What do these suggestions mean?
Removing the barriers to local arrangements for transfer could mean:

- extending joint financing, giving a 100% NHS contribution over 10 years, with tapering over a further five. NHS funds for joint finance could be drawn either from health authorities' own resources, at their discretion, or from an increase in the sums earmarked in allocations.
- a lump sum or annual payment from the NHS to the local authority for each person who crosses the barrier of care—what has become known as a portability grant. A key feature of this approach is flexibility. It would also have other advantages: there would be a direct relationship between the number of people cared for and the NHS funds available; health authority funding would not have to be confined to places in a particular local authority; arrangements could be developed gradually and locally.
- transferring hospital buildings from the NHS to local authorities, together with money to run them. “Such a scheme could effect the rapid transfer of all the in-patients of a hospital who no longer needed hospital care, together with their accommodation, and place in the hands of a single authority the task of providing the most suitable accommodation and care. It would, however, depend on the availability and suitability of hospital accommodation for this purpose".
- selling off hospital buildings, leasing them back from the purchasers to enable their inhabitants to keep a roof over their head while the capital gained goes into creating alternatives. The DHSS reckons that many hospitals are not well placed to provide a local service; if sale and lease back proves to be a practicable proposition, "it deserves to be carefully considered."

Promoting closer cooperation between health and local authorities could mean:

- pooling funds for a client group and planning services jointly. "Such an approach would aim directly at a key objective—using resources available for a client group to best advantage. It should be possible, for example, to run down hospitals for mentally handicapped people and build up community services in accordance with a detailed development programme. Voluntary bodies and housing and education interests would need to be consulted as part of such joint planning arrangements."

Transferring funds centrally or regionally could mean:

- a central transfer which would decrease NHS money and increase that available to local authorities—in the wider context, however, of the Government's policy of "sustained reduction in overall local government expenditure". As no immediate reduction in NHS services could be achieved, the sums transferred might need to be taken from whatever growth money was available to the NHS for those services. The proposal also raises questions about ensuring that the money goes where it's intended to: "local authorities have not, in the past, welcomed earmarking of funds allocated to them. . . Moreover such earmarking might be difficult to monitor without considerable bureaucratic intervention."
- earmarked central funds kept at central or regional level for local authorities to draw on. This avoids the difficulty of funds not reaching the places where they are needed, although there would still be administrative questions to be resolved. "An added incentive to local government to apply NHS funds available under this suggestion. .. might be to make it a condition that the local authorities should take over, within an agreed period commensurate with the resources available, those people who should not be in hospital."

Setting up a single agency for a client group could mean:

- making local authorities responsible for all services to mentally handicapped people, paying for those who remain in hospital on a contractual basis.'The advantage of such a scheme is that responsibilities would be clear and... the local authority would have incentive to move mentally handicapped people out of expensive hospital accommodation."
- establishing a single central authority at national level. "Such a body might act as a pressure group, but would have to work through health and local authorities. It could be strengthened by an allocation of funds to be used for transferring people from hospital to community care. However, problems of conflicting priorities at national level would arise, as they arise now, and it would be difficult to defend the establishment of such a body for one client group but not for others."

The DHSS has made it clear that it is not going to change whatever rules may need changing to enable more flexible use of available resources until the people who have them now and those who want them for the future have given their views. So the onus is on anyone with an interest in bringing mentally handicapped children out of hospital and preventing others from going in to let the DHSS know what they think. The topic may seem complex and remote from the needs of the small number of children from each health district and local authority patch now in hospital. But the shape of services available to them in future could depend on the response the DHSS gets to its suggestions.

The deadline for comments on Care in the Community is the end of 1981. Copies of the document are available from: DHSS Store, Health Publication Unit, No.2 Site, Manchester Road, Hey wood, Lancs. OL10 2PZ. Comments to: Planning and Prevention Division, Room D412, DHSS, Alexander Fleming House, Elephant and Castle, London SE1.

Meanwhile

Meanwhile the children now in hospital are growing older and cannot afford to wait for consultation, deliberation and possible new legislation. In Care in the Community the DHSS says that health and local authorities which want to press on with experiments "within the statutory framework" should go ahead.

The document cites one example of how the principle of the portability grant is being put into practice. Warwickshire social services department has reached agreement in principle with its Area Health Authority that it should act as its agent in providing a hostel with 20 places for mentally handicapped people in a building it already has, but is surplus to its requirements. The AHA will meet all the costs – about £100 a week for each hostel place, plus about £40 a week for each hostel resident who needs a place in an ATC. In return, it will have sole say in who lives in the hostel, and they will be people who either now live in mental handicap hospitals or are at risk of being admitted. People who are interested in teasing out the implications of this plan for mentally handicapped children now in hospital might just remember the lessons about the size of building and the advantages of ordinary rented housing that have emerged in this report.

Further information on the Warwickshire plan:
Bob Bessell, Director of Social Services, Shire Hall, Warwick.

Making a start

This report has given examples of ways in which health and local authorities and voluntary organisations are working to enable mentally handicapped children to leave hospital, in the context of a wider service to mentally handicapped children and their families. These examples are not, of course, the only ones in the country. Nor is there anything to say that other health and local authorities and voluntary organisations must work just as they do. As well as drawing on this particular set of experiences, they can get ideas for action from more general "blueprints": Mentally Handicapped Children: A Plan for Action (DHSS, 1977) offers one version of how an overall service might look; An Ordinary Life (King's Fund, 1980) offers another, in the context of comprehensive local services for mentally handicapped children and adults. And as well as examining these plans, health and local authorities and voluntary organisations can get in touch with a network of others across the country who share their aims and questions, and are working on the answers for their own particular locality.

Further information on the network:
Joan Rush, King's Fund Centre, 126 Albert Street, London NW1.

So the examples and experiences cited in this report offer just some of the starting points for people who want to welcome the children now in hospital to a developing local service. And they also show just how many and varied those people, and the organisations they work for, are.

As the examples of Wessex RHA and Northumberland AHA show, health authorities have a crucial part to play in planning to bring mentally handicapped children out of hospital. The role of local authorities is no less crucial. The Northumberland and Wessex examples also show how education departments need to be brought into planning from the start. The Camden example shows how a social services department which is committed to bringing all mentally handicapped children into its overall child-care philosophy and practice can set about it. The Camden example also shows how vital it is for housing and social services departments to work together. The Northumberland and Skelmersdale stories underline that close co-operation with housing departments is no less vital for health and voluntary organisations. The Leeds plan for long-term fostering offers another example of cooperation between voluntary and statutory bodies—in this case MENCAP and the social services department. The experience of Barnardo's in Skelmersdale and the Spastics Society at Beech Tree House illustrate how voluntary organisations can have an important experimental role. And voluntary organisations have perhaps a special part to play in pressing for a coherent philosophy towards all mentally handicapped children, and for the amalgam of different contributions that translate philosophy into practice.

The examples show too that those different contributions involve individuals as well as organisations. Most obviously, those individuals are the people who care for the children; the examples cited here make their own contribution to answering the questions currently being posed about the sort of training they should be offered. But the examples have a lot to say, too, about a whole network of people who have something to offer. GPs and health visitors, community mental handicap nurses, social workers, medical specialists, psychologists, physiotherapists, occupational and speech therapists—all crop up in these pages as people who have a part to play in creating opportunities for mentally handicapped children and in supporting those who care for them, whether these people are adoptive or foster parents, or caring staff.

As a start towards building new opportunities for mentally handicapped children now in hospital, all the different authorities, organisations and individuals might perhaps like to ask themselves the following questions and act on their answers.

Who are the children in hospital?

Does each local authority social services department know exactly which children from its area are in hospital, and where?

"Many social services departments are not even aware of the existence of many of their 'local' children who are living in mental handicap hospitals. Even if they are, it cannot be assumed that local authority staff have visited the child in hospital or the family at home, nor have they had the opportunity to participate in the kind of joint assessment of needs that we have advocated."
(Reference: *Helping Mentally Handicapped People in Hospital*, 3.4)

The National Development Group for the Mentally Handicapped wrote that in 1978. To judge from the response from local authorities in one region to North West MIND's 1980 questionnaire, not enough has changed. Yet it is hard to see how local and health authorities can together plan the best alternative for children now in traditional hospital wards until both at least know who they are talking about.

What are local authority social services departments doing to make sure they have this elementary information?

"The social worker best known to a child will probably be the one based on the hospital, but each child in hospital should be personally known to a social worker from his home social services department as well. This social worker should visit the child as often as possible and keep reports on him and on the conditions in which he lives in hospital. We are aware of the problems of maintaining a link between a child in hospital and the social services department of his home area, but it is essential that social work contact is established. Where there are hospital-based social workers, links should be made between them and the social services department of the child's home area. In other cases, it may be more expedient to make a direct link between the hospital and social work staff of the child's home area."
(Reference: *Helping Mentally Handicapped People in Hospital,* 3.4.6.iv.v)

What are hospitals doing to ensure that local authorities are in touch with all children in the hospital from their area? Are they in correspondence with them about each one?
"We suspect that many hospitals believe that local authorities have neither the resources nor the expertise to provide residential care for children now in hospital, and that it is not therefore worthwhile even trying to make contact with social work staff in the child's home area. This view might be based on the relatively high levels of ability and mildness of handicap of the 2000 or so children now in local authority residential care, but it is nevertheless misguided."
(Reference: *Helping Mentally Handicapped People in Hospital,* 3.49)

The NDG recommended that:

- hospital management teams should draw up a list of all children in order to relate each one to a given local authority area;
- the relevant local authorities should be approached (at Director level) to establish whether they accept that the children are in a sense residents of their geographical area;
- if they don't, hospitals may need to talk to the Director of social services for the area in which the hospital is situated; he may refer the case to the local authority association arbitration machinery, which will settle disputes when no authority accepts responsibility for a particular person.

Has all this been done?

What are the children's abilities and needs?

"The quality of assessment and record keeping in hospitals for the mentally handicapped is often far from satisfactory. Many children have either never been comprehensively assessed in the first place, or have not been re-assessed for some years. Their records are meagre to say the least, and contain little or no information on their present skills and abilities, far less a programme or plan on how these needs are to be met. Furthermore, even where there is a reasonable system of assessment, we have been surprised to note how seldom any systematic attempt has been made to involve staff from the appropriate local authority social services department. Even less common is evidence that the parents have had any opportunity to contribute to the assessment of needs and abilities."
(Reference: *Helping Mentally Handicapped People in Hospital*. 3.4.2.)

How true does this remain?
The NDG wanted to see an immediate, multi-disciplinary review of the needs of each child now in hospital. This review should lead to a recorded decision on the nature of those needs and ways in which they could be most appropriately and effectively met.

Has this yet been done for each child now in hospital?

How are the children's needs to be met?
In Chapter 5 of *Helping Mentally Handicapped People in Hospital*, the NDG went into detail on how assessment should be used as the basis for short-term planning to meet individual needs, with reviews of progress not less than twice a year. But it also said:
"A prime purpose of such reviews is to begin without delay to consider the possibility that the child's needs can be met outside the hospital. For this purpose, it is essential to involve the local authority from the start."
(Reference: *Helping Mentally Handicapped People in Hospital*. 3.4.5.)

And again:
"We realise, of course, that many children now in hospital are very severely handicapped, and that they undoubtedly require residential care. But the fact that they need residential care does not mean that such care must necessarily be given in hospital. We now know enough about a wide range of alternative methods of providing residential care, and recommend that these should be considered in the case of every child now in in hospital."
(Reference: *Helping Mentally Handicapped People in Hospital*. 3.4.8.)

Has each health and local authority, and each voluntary organisation, yet examined all those alternatives? Have they yet come together with the range of individual workers who will be involved in supporting mentally handicapped children who leave hospital? Are they planning, with them, the pattern of care and opportunity which will meet the individual needs of every child now in hospital, build on their abilities and offer them the foundation for growth and development to which they have a right?

Appendix: a few words on fund-raising from MENCAP

Kindly written by Mr. Edward Howe, National Appeals Director, National Society for Mentally Handicapped Children and Adults and included as an Appendix here at the request of the Department of Health and Social Security.

One can, of course, speculate ad infinitum on formulae for joint funding or other- wise of any project destined to meet social needs, but inevitably the voluntary source has to determine whether its financial strength is adequate to meet the demand or whether, bearing in mind the reason for the special finance, it is a viable operation to commence a special fund-raising campaign.

During the last fifteen years, and indeed in the last five in particular, the charity world, with its growing sense of competitiveness has begun to realise that fund- raising is a distinct profession. Overlapping slightly on public relations, marketing, commonsense and good luck, it requires that delicate balance of many arts and sciences that is able to achieve the very best return from any group of circumstances, no matter how scanty they may be. The writer, when requested by some hopeful organisation or individual to "tell us how to raise money" cannot resist comparing this situation with a patient in a surgery convinced that a complete cure requires only the swallowing of the right pills!

There is, as yet, no university diploma in fund-raising—perhaps we should invent a more academic measure to indicate achievement in this field—but at the moment, training leading to an impressive track record can only be acquired by experience. Field operators spring from at least three tough years at university— in other words, an Appeal Department. Needless to say, ample provision in the Department is given for students to study all branches of this work. This system has proved effective and possibly will achieve academic recognition in the future.

It is now a generally accepted fact that alternative provision must be found for the 15,000 mentally handicapped people in hospital, who have no reason for being there other than the complete inability of the statutory services to cope. From a fund-raising point of view, the prospects for an effective campaign are excellent. The recent expose spectacularly presented on the media certainly broke the ground in no uncertain way, but nevertheless the public is quick to forget unless stimulated by immediate reaction in the media and continuity of appeals activity.

The writer does not intend to detail his own specific plans for contribution to the overall effort that must be made to satisfactorily fund the voluntary side of this great problem. But, of course, it will be the theme to a whole series of complex sequences at the same time remaining separate from the general funding that must be the basic foundation to the existence of any charity.

It is as well, nevertheless, to consider a few ground rules to the development of a fund-raising campaign that are sometimes overlooked. Who do you know? Who are they? What is their background and potential? An idea is useless unless you have people to activate it, so get involved with people under any pretext. To sit at a desk and wonder why a scheme is not working is crass stupidity.

- Make sure that when people meet they gell and enjoy the experience. Dullness kills charitable interest instantly.
- Make sure they all clearly understand what they are meeting for; have everyone badged to facilitate contact and have plenty of visual material for impact.
- Don't be opulent, but don't penny-pinch. If you feel like giving your helpers a glass of champagne, why hesitate (as long as it is donated).

In other words, you are forming a committee to help but the biggest mistake of all is to call them a committee – those days are really over.

Remember, the magic button is just around the corner. You must have the skill and determination to look and then the courage to press the button. The SAS say he (or she) who dares, wins that's OK, providing you do not put too much charity money at risk.

And finally, if a super idea is initially successful but its effectiveness depends on how long you can keep it under wraps, you need good security, and this emanates from a loyal and trustworthy staff.

September, 1981