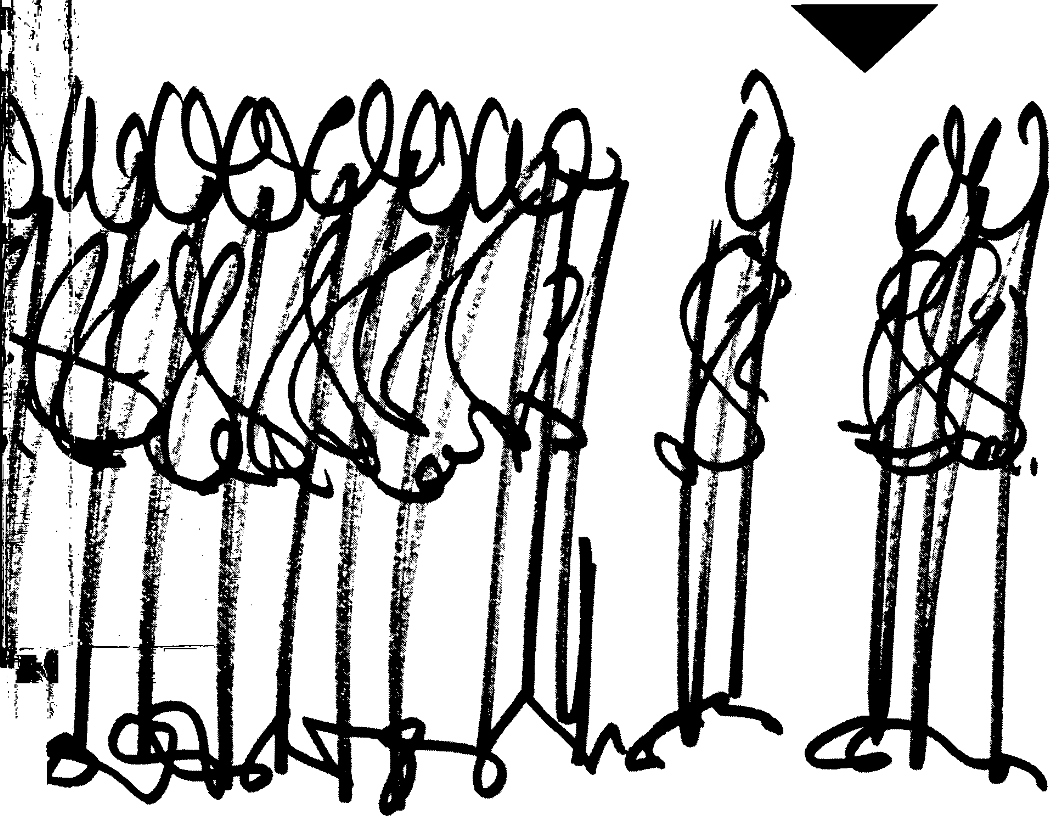
Ann Richardson and Jane Ritchie

MAKING THE BREAK



'Parents' views about adults with
a mental handicap leaving the parental home.

King Edward's Hospital Fund for London

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CONTENTS

INTRODUCTION

PARENTS' PERSPECTIVES

IMPLICATIONS FOR POLICY

List of tables

FOREWORD

Recent years have seen major developments in the philosophies influencing services for people with mental handicap and their families. These philosophies have informed a wide range of initiatives – typically on a small scale – which aspire towards securing an ordinary life for people with mental handicap. In turn, the modest successes achieved through these new services have contributed to the pressures for larger-scale change now underway in some parts of England and Wales.

This sense of progress may however be deceptive. As the House of Commons Social Services Committee argued in its detailed study of community care, performance in developing community-based services is running rather short of the policy rhetoric. The main thrust of current efforts are focusing – through the deinstitutionalisation programme – on providing more appropriate services to people already 'inside' the welfare system. Underpinning these developments is the reality that the majority of *adults* with mental handicap continue to live in the parental home. The new patterns of residential care, the growth in day and domiciliary services, the recent rediscovery of the importance of supporting informal carers – all still leave parents as the main providers for their handicapped sons and daughters.

Of course, such family life can be a source of great mutual reward. It is also bound to invest parents with a heavy weight of responsibility as they confront the dilemmas involved in articulating the interests of different family members, helping their handicapped son or daughter live a full life and planning for the future – a future which must almost invariably involve the person with mental handicap leaving the parental home. The ways these dilemmas are addressed will in one sense be unique to each family: they will be shaped however by wider public expectations about family responsibilities and the status of adults with mental handicap, by the information available to parents about the opportunities (for a more independent home life, for example) offered by public and private services, and by their experiences with welfare professionals.

The main strength of *Making the break* is precisely that it sets out to understand and illuminate these issues from the perspectives of parents. It also goes beyond description and analysis to draw out implications for public policy and professional practice. It argues that parents need more accessible information and much more support, provided over a more extensive period of time, than appears to exist at present. In elaborating this argument, more detailed proposals are again clearly related to the views and experiences of parents.

It is to the credit of Ann Richardson, Jane Ritchie and their research collaborators that this work has been undertaken with great sensitivity and skill. Their report helps to fill a significant gap in the existing literature and is an important addition to King's Fund publications related to the *An Ordinary Life* series. The views and proposals presented here deserve to be considered carefully by everyone concerned to ensure that modern philosophies of community care are actually reflected in a better deal for people with mental handicap and their families.

David Towell
1986

PREFACE

This paper is addressed to a wide range of people concerned with the provision of care for people with a mental handicap and their families. It is the result of research among parents whose adult handicapped sons and daughters live at home and explores their perspectives on the eventual move from the parental home. Focusing, on issues surrounding the timing of this move and the nature of the provision sought, this paper should interest those responsible for managing and planning arrangements for residential care and those involved in providing support to families.

The majority of people with a mental handicap live at home with their parents – not only when they are children but also when they are well into adulthood. The question of their move from home is the subject of increasing concern among many professionals and parents, primarily because of the large number of people with a mental handicap who live with elderly or frail parents. It is not just a case of finding somewhere for them to live; if the move takes place too suddenly, there may be no time to ease the transition to their new surroundings. There is, additionally, a growing interest in the potential for younger people with a mental handicap to move out of the parental home in much the same way as most young people do.

Although addressed to people concerned with policy, this paper has as its core an issue which is not a 'policy' decision at all. Put simply, this is the question of whether a son or daughter with a mental handicap should leave the parental home and, if so, at what point. Clearly, this decision is one which is taken – and should be taken – by individual families. But surrounding this central question, there are a number of issues which must be faced by those responsible for policy and practice in the field of mental handicap. What kinds of residential provision should be developed and how much? To what extent should professionals take an active stance in encouraging parents to make the decision to let their son or daughter move on? What specific help should they provide to assist parents prepare for the move, see it through and adjust to their very changed circumstances once it has taken place?

Because of our concern to present these issues in an accessible form, this paper is purposely brief. It has three main sections. The first introduces the nature of the issues involved and reviews recent policy statements and research in this area. The second presents a summary of the conclusions of our research on parents' perspectives on the move from home. The third explores the implications of our findings for policy. The text is supplemented by a number of 'case studies' of individual families, providing some 'feel' for the issues as seen through the eyes of people in different circumstances. All names, of course, have been changed to avoid identification.

A book which considerably extends the discussion of these issues is under preparation from this research. It explores many of the same questions in greater depth and is directed to a much wider audience. In addition, a short paper on the data from the postal survey is available from SCPR.*

We would like to express our gratitude to those who contributed to our research. First, the Joseph Rowntree Memorial Trust provided us with the necessary financial support. Second, a small advisory group (Jan Porterfield, Oliver Russell and David Towell) gave us consistently sound advice throughout the study. Third, our co-researchers, Jill Keegan and Kit Ward carried out the interviews with all the necessary sensitivity and understanding and with consummate skill. The richness of the information collected and the depth of analysis therefore made possible are a tribute to their involvement. Finally – and most important of all – the contribution of the parents involved in the research must be acknowledged. Our study asked them to explore their inner thoughts, doubts and anxieties on one of the most difficult questions any parent has to face. We hope our presentation of their position does justice to the depth and honesty with which they responded.

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INTRODUCTION

Introducing the issues

Living arrangements for people with a mental handicap have been the focus of considerable attention in recent years. There has been concern that more places should be provided and that the range of options available should be increased. Particular interest has been expressed in enabling people with a mental handicap to extend their capacity for independent living. But the greater part of this discussion has been directed to the needs of handicapped people currently living in hospitals or other large institutions. The needs of the much larger population, those currently living at home with their parents, have been generally ignored.

Some interest in this group, however, has begun to surface for two separate reasons. First, there is concern about the considerable number of handicapped people who live with elderly or frail parents. The possibility of a sudden death or illness leaves them at risk of an abrupt and unplanned move from their parents' home. It is not just that this group may need somewhere to live; they require time to become emotionally prepared and familiar with their new surroundings before a crisis occurs.

Second, there is increasing interest in the potential for handicapped people to leave their parental home as they pass from adolescence into adulthood and to have access to the full range of options available to non-handicapped people. Applying to all areas of living – employment, leisure activities, friendship and marriage – it is particularly important in relation to where and how handicapped people live. There is particular concern to provide facilities and support to enable them to live as independently as possible. As in the case of those moving from the home of elderly parents, there is a need not only for somewhere to live but also for considerable help in making the transition.

Although the residential provision required by people with a mental handicap who live at home and those who live in hospital may be very similar or even identical, the issues raised by their move are very different. This is not simply a question of who makes that key decision, although that in itself is important. The difference also arises from the very distinct nature of the situation from which they come. In the case of those living with their parents, longstanding feelings about 'home' necessarily serve as the principal reference point for assessing any other arrangement and must heavily influence any willingness to move on. For the parents, their son's or daughter's preferences may be compounded by their own feelings about having him or her at home. The move from hospital is essentially about moving from one form of residential arrangement to another. The move of sons and daughters from home, in contrast, involves family members 'making the break' from each other. The issues raised are much more complex.

This paper addresses two central policy issues. First, do parents want to continue to look after their children until they can no longer cope or, alternatively, to see them settled elsewhere before that time? To what extent do they seek help with respect to making a break from their handicapped sons and daughters and of what kind? Second, what kinds of residential care are parents looking for, either now or in the longer term? To what extent does this differ from what is currently on offer? These broad questions must be set, however, in the context of the nature of parents' situations and their feelings and assumptions about home care.

The research

This study was carried out primarily in two local authority areas and involved four distinct approaches. First, in order to develop a profile of the circumstances of parents with a mentally handicapped adult son or daughter at home, a postal survey of all parents known by local statutory and voluntary agencies was carried out. Second, in order to explore their feelings about seeing their son or daughter leave home and their experience of alternative care, just under 50 parents currently caring at home were interviewed in depth. Third, these discussions were complemented by a small number of interviews with parents in another area whose son or daughter had already left home. Finally, as a means of exploring parents' views about the most appropriate form of care for their son or daughter, six discussion groups were held with parents, in sets of about eight. A fuller description of the research methods employed is provided in Appendix B.

Two issues arising from the nature of the research deserve brief comment here. First, apart from the postal survey, the data are qualitative rather than quantitative in form. Using qualitative research methods enabled us to achieve some insight into the highly sensitive issues concerned. At the same time, however, the approach precludes us from making statements about the relative numbers with different views or experiences, since large numbers of interviews involving quantifiable questions were not attempted. Thus, we cannot say with any precision how many parents feel one way and how many another, nor whether any approximate weightings are statistically 'representative'. Nonetheless, we would claim for the data a level of understanding which could not be relayed through the prescribed methods needed for large scale studies.

Second, it may be questioned why we did not interview the handicapped people themselves. There is no doubt that this would have provided valuable information. Many have experienced residential care, often on a short-term basis, and most would have been able to give their views about moving out of their parents' home. But this is a difficult subject, which would need to be handled with extraordinary care. We were concerned that people with a mental handicap might find the interview distressing or alarming, especially if they had not realised that they might eventually need to move from home. Moreover, the research was conceived and designed to focus on parents, since their views have a major influence on how and when the move from home takes place. We believed that a notably different research strategy would have been required if the handicapped people were to form a major part of the study.

The two authorities chosen for the research were selected to provide some variation in the nature of their provision and the traditions of their population. The first, in the south, covers a large geographical area near London. It has a particularly active policy in the field or residential provision for people with a mental handicap. A large number of hostels, run on rehabilitative lines, prepare residents for a move to more independent accommodation and also provide short-term care for families. The principal mental handicap hospital has been reducing its numbers in recent years and is not viewed as a resource for people moving from the parental home.

The second authority, in the north, is much smaller in size and population. It has a particularly active policy with regard to day care for mentally handicapped people. There is a community mental handicap team involving professionals from a range of different specialisms. This authority's hostels provide fewer places and are more traditional in orientation, but they also provide short-term care for families. The principal mental handicap hospital, as in the other area, is not seen as a resource for people moving from the parental home.

The question of numbers

A crucial question for any policy issue is how many people are involved. The question here is how many people with a mental handicap are currently living at home, particularly those who are already adult. The difficulty of estimating with any precision the number of mentally handicapped people in the population at large has been widely documented and the arguments need only be briefly rehearsed here. There is no single established definition of this group and no census on their numbers, however defined. One of the more common definitions suggests a person with a mental handicap to be someone 'who does not develop in childhood as quickly as other children nor attain the full mental capacities of a normal adult'.[1] The measurement of the population falling within this rather loose definition is clearly not possible with any exactitude.[2]

Nonetheless, a number of estimates of the population with some form of mental handicap have been made, using data on births as well as usage of various services. From these it has been suggested that although prevalence probably varies considerably from one area to another, there are approximately 140,000 to 170,000 mentally handicapped people living in England and Wales.[3] Of these, it has been estimated that over 60,000 live in hospitals, local authority hostels or similar provision; the remaining 80,000 to 110,000 live at home with their families.[4] These figures, however, do not include all people with a mild mental handicap; one recent publication suggests that the number of people who have at some stage come to the attention of educational and other services for reasons of such handicap is in the order of 400,000.[5]

As our study is solely concerned with adults living at home, some estimates of this population would be useful. In fact, there seem to have been few efforts to estimate their numbers with any precision. One publication suggests that there are roughly 40,000 severely mentally handicapped adults in the United Kingdom who live with their families.[5] Not all of these are living with their parents, as some will have moved on to the home of a sibling or other relative, but it can reasonably be assumed that the majority are in the parental home. The numbers would be much greater, of course, if the people with more mild handicaps were also included. A reasonable guess is that there may be up to 100,000 people living at home with their families who may be actual or potential users of mental handicap services.[6] In any case, the exactness of these numbers is not an issue here; they provide a rough order of magnitude for considering the number of people affected by the question of a move from home.

The issue of alternatives to home becomes more pressing as parents age and some information on the age distribution of this population would be of interest here. Regrettably, this is even more imprecise, but a number of studies have found that about one-third of the parents with mentally handicapped adults living with them are aged 65 or over. Indeed, substantial numbers are not only elderly but living without a spouse, so that the need for alternative care is avoided solely by their survival.[7] The findings of our own study, which support such evidence, are outlined in the relevant section below.

The policy context

Most of the issues with which this paper is concerned are local ones. Within the given resources, it is up to individual local authorities and health authorities to decide how much provision to make for people with a mental handicap and of what kind. It is also up to them to decide how much they should take an active stance with individual families to help them think about, and possibly undergo, the move of their son or daughter from home. As with most locally-taken decisions, policies and practices on these questions differ widely from one area to another. In some areas, the social services department clearly intends to tackle this task on its own, whereas in others there appears to be greater partnership with voluntary organisations and health authorities.

But these decisions are not made in a vacuum. The central government is in a position to affect policies considerably through the development of particular programmes. The Care in the Community programme, concerned with the needs of people moving from long-stay hospitals, provides an excellent example. Furthermore, a climate of opinion about the appropriateness of particular policies tends to provide a key context for local decision-makers. This may derive both from official policy statements on the issues in question and from research and writings by other interested individuals and organisations. A brief look at some recent comments is in order here.

Any government's policy stance on decisions made within individual families is likely to be a matter of some sensitivity. On the one hand, it would be wholly unacceptable for parents to be told when their son or daughter should leave home or where he or she should go. On the other, there is an obvious need to make some estimate of potential demand for residential care. Successive governments have consequently had to make some assumptions about the care of mentally handicapped people within their families. These have been stated with varying degrees of explicitness. The 1971 White Paper, while challenging the relative roles of hospitals and other providers of residential care, assumed that there should be no major shift in the role of parental care. Indeed, it argued that each handicapped person should live with his or her family 'as long as this does not impose an undue burden on them or him'.[8] The subsequent DHSS review in 1980, *Mental Handicap: Progress, Problems and Priorities,* did not question this position, although it did note the lack of evidence about the scale and nature of unmet demand for residential care.[9] Both documents, it should be added, were concerned that services to help parents caring at home be increased.

The assumption underlying the White Paper's position that living at home is essentially 'best', was first subjected to official challenge in the report of the Jay committee's enquiry into nursing services, published in 1979. Influenced by the growing interest in the rights of handicapped people and arguments for 'normalisation', it set out the principle that 'any mentally handicapped adult who wishes to leave his or her parental home should have the opportunity to do so'.[10] Living in the parental home was thus not to be seen as self-evidently the best arrangement for the person with a mental handicap. Indeed, the committee argued that the family should not be viewed as 'the central agent in care and support until parents are old and infirm', but that the community and professional services should assume much greater responsibility.[11]

The government accepted 'in principle' the Jay committee's basic model of care, as set out in the DHSS policy paper *Care in Action* in 1981. It urged local authorities to develop the capacities of mentally handicapped people for independent living. The central dilemma posed here, however, was side-stepped. Authorities should 'enable mentally handicapped people to live with their families where possible, or failing that in a local community setting'.[12] The need to consider alternatives to home was somewhat expanded, however, in the latest report from the National Development Team published in 1985. This noted the aim of a 'community-based service' for both health and local authorities to be to develop services to 'enable mentally handicapped people to remain with their families if they both wish it, and when this ceases to be desirable or possible to ensure that appropriate alternative provisions are available for them.[13] Indeed, a DHSS report on mentally handicapped people with special problems had also stressed the need for an independent life for this group: 'children should be helped to remain with their families and adults helped to remain within their own local community'.[14]

Official policy regarding provision for mentally handicapped adults was subjected to renewed scrutiny very recently in the enquiry of the House of Commons Social Services Committee into Community Care. Its report, published in 1985, was primarily concerned with those people who were currently in hospital or likely to need hospital care in future. Nonetheless, it acknowledged the need for policies for those currently living in the community, including their families, arguing that more attention should be given to their problems.[15] Indeed, it argued strongly for the participation of families in the planning process in order to make services more responsive to their needs: 'all agencies responsible [should] ensure that plans for services are devised with as well as for mentally disabled people and their families'.[16]

What the report did not do was to confront the underlying problem of whether government policy should encourage the movement of mentally handicapped adults out of parental homes. Instead, its principal concern in this area was the 'approaching crisis'[17] arising from the large numbers of handicapped people living with elderly parents. The question 'what will happen when I die?' was said to be 'a common-place' in discussions of mental disability, but 'answers come less easily'.[18] It urged local authorities to estimate the numbers involved and to inform the Department of the service consequences. Interestingly, the effect of family care on the demand of residential provision was noted explicitly in the response of the DHSS to this report. While the total places needed had not altered substantially since the White Paper, it was suggested, this estimate must be used 'bearing in mind that the level of family support available will, to some extent, influence the provision required'.[19]

A number of organisations are bringing to public attention the problem under discussion here. Advocates of 'normalisation' are particularly concerned with the timing of the move from home and the importance of training for independent living.[20] The Campaign for People with Mental Handicaps (CMH), for example, in its evidence to the Select Committee, strongly endorsed the Jay committee's position that mentally handicapped young people should have the chance to leave home if they wish.[21] Similarly, the

Independent Development Council for People with Mental Handicap argued that service providers should be accountable directly to the client (not the parent) and pressed for early preparation of both for a move from home.[22] This group had even more clearly acknowledged the potential conflict within families in its 1984 report, which stated 'in determining choice, it must be remembered that people with mental handicap and their parents have separate and sometimes differing requirements'.[23]

With respect to the kinds of provision which should be made for people with a mental handicap, there has been extensive interest over recent years in devising new and innovatory approaches. Much of this has focussed on means of making their housing as close to 'normal' housing as possible. Such concern derives heavily from arguments surrounding the principle of normalisation, directed to both the physical and the psychological aspects of housing. It is argued, for instance, that people with a mental handicap should be 'in the mainstream of life, living in ordinary houses in ordinary streets, with the same range of choices as any citizen'.[24] It is also argued that handicapped people 'share the universal, fundamental desire for a home of one's own, a private place, a place to which we can retreat, where we can be ourselves . . .'[25] There is a growing literature on this question; a few useful references are cited for convenience.[26]

Some research findings

Despite the considerable interest in the forms of provision to be made for people with a mental handicap, there has been surprisingly little research on the perspectives of parents on the move from home. What there is has tended to chronicle parents' deep concern about the issue, combined with their adaptation to an expectation that nothing much can be done. The pioneering study by Michael Bayley, for instance, found that few families with handicapped adults had any idea of what would happen when they could not cope: 'Anxiety about the future pervaded the life of most if not all of these families', he concluded. 'If they could be given the sure knowledge that their [son or daughter] would be looked after in a way that would satisfy them, a great load would be lifted from them.'[27] A larger-scale study of parents suggests that worries about the long-term future tend to be greatest among those with a severely disabled son or daughter.[28]

A small study of elderly parents by Alison Wertheimer, noting the 'strong mutual bond of affection between parents and handicapped person,[29] suggests that this fosters an acceptance that the son or daughter will remain at home indefinitely. She concludes that 'an "abnormal" or atypical social pattern has become normal in these families with one or both parents seeing themselves not as one of a couple but as a threesome'.[29] This view is echoed by early results from a study in Wales which found parents to show a great sense of affection for their sons and daughters and little trace of resentment at their current situation. With respect to the future, there were a number 'who found this subject difficult to talk about ... almost a taboo. For these people, life seemed to be lived on a day-to-day basis in the vague hope that a magical solution might turn up'.[30] Another study, however, finding parents to prefer to keep their son or daughter at home, concluded in contrast that this arises because of 'both the inacceptability of the options of which they were aware and their lack of knowledge of possible alternatives'.[31]

A particularly interesting study by Hugh Card for East Sussex County Council suggests that the reason so many parents want to keep their son or daughter at home stems from the nature of the parent-child relationship. He argues that parents cannot look on their handicapped son or daughter as adult, or capable of independence, without the normal experience of rejection during the period of adolescence. He notes: 'The process whereby adolescents become independent from their parents is one in which the onus is on the child. Frequently the child will have to exert considerable force in order to break away from the parents' protective behaviour'.[32] As this commonly does not occur in the case of adolescents with a mental handicap, parents cannot make the adjustments which would be required by separation. 'Without the initiative from the child many parents are not prepared to face the pain and loss involved in readjusting to a new and more separate relationship with their adult offspring.'[32]

Finally, one study which deserves a mention here is the book on short-term care by Maureen Oswin. Her focus is not the move from home and her book centres on children with a mental handicap, rather than adults, but she strongly highlights the need for sensitivity among professionals in handling separations from home. She wrote: 'It seemed that very little concern was being shown to mentally handicapped children as children, but their image as burdens to their families was much emphasised.'[33]

A profile of families caring at home

Who are the mentally handicapped people living at home? What is the nature of their circumstances and that of their families? It seems useful to provide some basic information here. The following data derive from our study in two local authority areas; the respondents comprised 453 families in the southern area and 177 families in the northern, all having at least one mentally handicapped son or daughter at home. Some families had two (20 families and 7 families respectively) in which case we collected information only on the elder. We must note that it would not be appropriate to aggregate formally the two samples, and consequently we present the information in table form on each area separately. Conveniently, they are very similar and can be discussed together. The tables can be found at the end of this section.

The parents A substantial number were found to be quite elderly; in over a quarter of the households, both parents or the sole parent were aged 65 or over and in nearly half, the 'main carer' (the sole parent or the mother) was aged 60 or over (see Tables 1 and 2). About one-third of the parents were in single parent households; this was mainly because they were widowed, although a few were divorced or separated (Table 3). The fairly low level of marital breakdown is notable, given the common assertion that this tends to be high among parents with mentally handicapped children. (It may, of course, be higher among parents whose son or daughter is no longer at home.) Most of the households comprised just the parents and their handicapped son or daughter, but about two-fifths contained other children (Table 4).

Most parents were not in work, mainly because they were retired; only two-fifths and one-third of the household heads respectively were in full-time employment. Although the majority of parents reported they were in good health, this was a very bare majority in the northern area, where considerably more indicated their health was only fair or poor (Table 5). It should be stressed that this was solely a self-assessment. With respect to tenure, half the households in each area owned their own home, with most of the remainder renting from the local authority. It is also worth noting that a very substantial majority in each area (about four-fifths) belonged to one or more parents' organisations, such as Mencap or an adult training centre parent-staff group.

The sons and daughters with mental handicaps Roughly half were under age 25 and half were aged 25 or over; a few were in their forties and fifties (Table 6). They were fairly evenly divided by gender. The great majority in both areas (over four-fifths) attended an adult training centre or special care unit during the day; a few had some form of employment and some stayed at home all day (Table 7). To provide a very rough measure of the severity of their handicap, we created a four step scale (very mild, mild, severe, very severe), based on parents' indication of their abilities in a number of spheres (ability to dress, feed themselves, use public transport and so forth); this is described more fully in Appendix B. We found that they spanned a wide range of handicap. In the southern area, about two-thirds were mildly handicapped (including two-fifths very mildly) and the remainder severely handicapped (including one-sixth very severely). In the northern area, over half were mildly handicapped (including one-quarter very mildly), with the remainder severely handicapped (including one-fifth very severely). These differences, of course, may in part reflect differences in parental assessment (Table 8). About a quarter and a third respectively had an additional physical illness or disability, such as spasticity or epilepsy. In addition, most were said to have one or more behavioural problems, such as becoming overactive or excited or very withdrawn.

Elderly parents Because of the particular problems of elderly parents, some additional information is set out about them here. First, although their sons and daughters tended more commonly to have a mild handicap, there were nonetheless considerable numbers caring for a son or daughter with a severe handicap. Indeed, among the households where both parents (or the sole parent) were aged 65 or over, the proportion caring for a son or daughter with a severe handicap was nearly one-fifth and nearly one-third respectively (Table 9). Second, large numbers of elderly parents were found to be living alone with their son or daughter; that is, with no surviving spouse. Roughly half of all 'lone parents' in each authority were aged 65 or over (Table 10). Looked at the other way, in one authority half the parents aged 65 or over were on their own (66 out of 130) and in the other the equivalent proportion was three-fifths (28 out of 46). To emphasise the numbers more clearly, there were 26 parents aged 75 or over caring for a handicapped son or daughter on their own in one area and 14 such parents in the other.

Summary Considering the two samples together, there are remarkably few differences in the two populations. The age distribution of the parents in each area was surprisingly similar, as was their marital situation. Roughly the same proportion of households included other children. As noted, fewer parents in the northern area reported themselves to be in good health and fewer were in full-time employment. Tenure patterns and membership of voluntary organisations were virtually identical. With respect to the handicapped sons and daughters, the only notable difference was that those in the northern area were, on average, reported to have more severe handicaps.

It might be added here that it is difficult to assess the representativeness of our samples. Collecting the data proved to be a complex exercise. Despite considerable efforts to locate all parents in each area with adult handicapped sons and daughters at home, it is likely that some were missed. In addition, our response rates (62 and 68 per cent respectively), while reasonable, may reflect some hidden bias. It is notable, for instance, that a high proportion of our sample belonged to a parents' organisation. It may also be significant that a high proportion of the sons and daughters attended an adult training centre, although this may reflect the particular policies of the two areas studied. It is not possible, however, to check the characteristics of the 'missing' families. A fuller discussion of our research methods is provided in Appendix B.

This information has been set out here to provide a context for our discussion about parents' perspectives on the move from home. Our study was not essentially 'about numbers' and our subsequent interviews were not randomly selected from the total relevant population but purposely chosen to cover a variety of circumstances.

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Table 1 Age of parents/parent

	Area 1		*Area 2*	
	Number	%	*Number*	%
Both (or lone parent) under 65	285	63	118	67
One under 65/one 65 or over	37	8	9	5
Both (or lone parent) 65 or over	124	27	47	27
Not given	7	2	3	2
	N=453	100%	N=177	100%

Table 2 Age of main carer

	Area 1		*Area 2*	
	Number	%	*Number*	%
Under 40	9	2	7	4
40–49	77	17	33	19
50–59	147	32	54	31
60–64	84	19	32	18
65–74	95	21	34	19
75 or over	35	8	15	8
Not given	6	1	2	1
	N=453	100%	N=177	100%

Table 3 Marital status of parents

	Area 1		*Area 2*	
	Number	%	*Number*	%
Married	317	70	113	64
Widowed	108	24	51	29
Divorced/separated	24	5	8	5
Single	1	–	–	–
Not given	3	1	5	3
	N=453	100%	N=177	100%

Table 4 Household composition (in addition to son/daughter)

	Area 1		*Area 2*	
	Number	*%*	*Number*	*%*
No one else	89	20	36	20
Husband/wife	283	62	98	55
Other children under 16	44	10	21	12
Other children 16 or over	167	37	67	38
Other relatives	15	3	11	6
Other non-relatives	6	1	–	–
Not given	10	2	5	3
	N=453	135%*	N=177	134%*

* Households with people in more than one category (for example, husband and other children) are coded more than once.

Table 5 Health of main carer

	Area 1		*Area 2*	
	Number	*%*	*Number*	*%*
Very good	111	25	34	19
Good	176	39	56	32
Fair	122	27	62	35
Poor	28	6	12	7
Very poor	5	1	5	3
Not given	11	2	8	5
	N=453	100%	N=177	100%

Table 6 Age of mentally handicapped son/daughter

	Area 1		*Area 2*	
	Number	%	*Number*	%
18–24	164	36	72	40
25–29	90	20	23	13
30–39	145	32	56	32
40–49	40	9	14	8
50–59	4	1	5	3
60 or over	1	–	–	–
Not given	9	2	7	4
	N=453	100%	N=177	100%

Table 7 Day-time activity

	Area 1		*Area 2*	
	Number	%	*Number*	%
Adult Training Centre	352	78	138	78
Special care unit	30	7	18	10
Sheltered workshop	8	2	3	2
Work (full or part-time)	20	4	2	2
Stay at home	42	9	17	10
Do something else	10	2	–	–
	N=453	102%*	N=177	102%**

* 9 people had more than one day time acrivity.

** 1 person had more than one day time activity.

Table 8 Severity of handicap (from index compiled by researchers)

	Area 1		*Area 2*	
	Number	%	*Number*	%
Very mild	180	40	45	25
Mild	134	30	54	31
Severe	81	18	40	23
Very severe	58	13	38	21
	N=453	100%	N=177	100%

Table 9 Parents' age by severity of handicap

	Both (or only) under 65		*one under 65/ one 65 or over*		*Both (or only) 65 or over*	
	Number	*%*	*Number*	*%*	*Number*	*%*
Area 1						
Handicap:						
Very mild	101	35	14	38	63	51
Mild	80	28	16	43	37	30
Severe	56	20	6	16	16	13
Very severe	48	17	1	3	8	6
	N=285	100%	N=37	100%	N=124	100%
Area 2						
Handicap:						
Very mild	28	24	–	+	15	32
Mild	33	28	3	+	17	36
Severe	27	23	3	+	10	21
Very severe	30	25	3	+	5	11
	N=118	100%	N=9	+	N=47	100%

+Base too small for percentages.

Table 10 Age of main carer by family circumstances

	One parent		*Two parents*	
	Number	*%*	*Number*	*%*
Area 1				
Under 59	42	32	190	60
60–64	22	16	62	20
65–74	40	30	55	17
75 or more	26	20	9	3
Not given	3	2	1	–
	N=133	100%	N=317	100%
Area 2				
Under 59	15	25	77	68
60–64	16	27	16	14
65–74	14	24	17	15
75 or more	14	24	1	1
Not given	–	–	2	2
	N=59	100%	N=113	100%

PARENTS' PERSPECTIVES

Three families

On thinking about a possible move of a handicapped son or daughter from home, parents necessarily hold one of three broad positions. First, they may be fully confident that their son or daughter should remain at home until they, as parents, can no longer cope. Second, they may be tuned to the need to consider the issue at some point but essentially ambivalent about the desirability of any move. Finally, they may be actively seeking to find alternative care either urgently or in the immediate future. Those taking each of these positions do not necessarily share identical circumstances nor view their parental roles in the same light. As a means of introducing and illuminating these stances, we offer three brief sketches of families from our research.

ELIZABETH, age 37, is a woman with a severe mental handicap who lives alone with her mother, now nearly 80. Her father, to whom she was very close, died only very recently. She attends an adult training centre during the day and her mother, despite her age and circumstances, does not seem overwhelmed by the job of providing her care. Elizabeth has never lived away from home, although she spent two weeks in the local mental handicap hospital some years ago when her parents had a holiday. Unfortunately, this experience was such an unhappy one that her parents never enquired further into alternative care.

There was never a time when Elizabeth's parents seriously questioned looking after her at home; it was always assumed that mentally handicapped children, like other children, belonged at home with their parents. They also assumed that the responsibility for caring for them should pass to other family members when they could no longer cope. Their other daughter, now in her early fifties and living on her own, has agreed to take on this care when appropriate. Although Elizabeth's mother was forced to rethink her situation when her husband died, her position is now clear. Mother and daughter provide company for each other and she, the mother, would be 'lost' without her daughter. As she says: 'I've looked after her all these years. I can do so a bit longer'. And furthermore: 'they (a staffed hostel) wouldn't look after her like I do'.

JULIE is 29 and has Down's syndrome. She lives with her parents, now in their 70s, and attends an adult training centre during the day. Her mother describes Julie as a 'bright, very happy person who is very at ease with other people'. She is able to do everything for herself and helps a great deal at home. Julie has a close relationship with both her parents, but particularly with her mother. She sees her daughter as the centre of her life, her 'very, very life' and feels lost when she's away. As she says: 'As long as I have any breath in my body, I want to hold my Julie with me. Right to the very last. I don't want to part with her, I never want to part with her; she's too much part of me.'

But deep down, Julie's mother knows that this course is not necessarily in her daughter's interest. She recognises that Julie would probably settle quite happily at the local hostel, where she has already spent an enjoyable week. Julie would probably like being with her friends as well as with the staff whom she knows and likes, and the hostel is close enough for her parents to see her regularly. Ideally, Julie's mother would like to see her settled before anything happens, but cannot contemplate initiating action towards her daughter leaving home. Yet she feels that if someone were to suggest it to her, she would be quite responsive. 'If they say to me: "Now, look, Mrs —, you're being unkind to Julie; it's time she was on her own" then I would say straight away "well, if you really think like that, that I'm doing more harm than good to Julie, then I would have no say in the matter".' She adds: 'But I want them to suggest it . . . I don't want them to think I'm pushing my child on . . . I don't want them to think I'm saying "please, will you take her?"'

HENRY is 20 and has a mild mental handicap. He is an able youngster but suffers from severe epilepsy. This, his mother believes, causes his distressed and sometimes violent behaviour. Henry's parents have looked after him since birth, except for a four-year period in which he was in a hospital school and several short stays in a local hostel and the local mental handicap hospital. Although he attends an adult training centre during the day, his mother and father jointly find it a great strain on their household to have him living at home. They have had very little help from relatives or anyone else and at times their marriage has been under considerable stress. For some time now, they have been trying to find alternative care for him on a long-term basis.

The situation appeared to have been resolved when, with the help of a social worker, a place was found at the local hostel. Both parents felt it was good and, although not perhaps their ideal, hoped Henry would be able to remain there long-term. Unfortunately, he not only preferred home but insisted on 'running away' back to home at every opportunity. To date, they have been unable to persuade him to stay there and are unwilling to force hostel (or hospital) care on him. They now expect him to remain at home for the foreseeable future, as there is no other realistic alternative. Both seem resigned; in his mother's words, 'we feel we made him and we've got to do our best for him' and in his father's, 'we've got him for life'.

These brief descriptions cannot do justice either to the complexities of the individual family circumstances outlined here or to the many other scenarios found among other families. They serve, rather, to illustrate some of the issues surrounding a consideration of the move from home by any parent. These include not only attitudes to known alternatives but also a whole range of beliefs and feelings concerned with care in the home. In order to supplement these descriptions, and illuminate further many of the dilemmas outlined in the following sections, we have also prepared a series of case studies arising from our study. These are set in distinct type, so that they can be read independently from the surrounding discussion.

Caring at home

Mentally handicapped people cannot be described as if they were a homogeneous group. Their individual behaviour, dispositions and needs differ as they do among any other particular population. Although they have a 'special need' in common, this too can vary greatly depending on the nature of their handicap, any associated physical or behavioural problems and the range of abilities they have been allowed to develop. This is particularly relevant with respect to the questions of interest here. Looking after a son or daughter with a mild mental handicap is a very different proposition from looking after one with a severe handicap. Caring for someone with serious physical disabilities presents additional special problems. Because these matters deeply affect parents' disposition to continue to look after their son or daughter at home, some comments are in order about what caring at home involves.

IAIN is 18 and lives with his two parents (aged 46 and 44) and a younger brother and sister. He is a sensitive and affectionate youngster, very aware of other people and close to family and friends. He is active, lively and has a number of keen interests. Iain, however, has a severe mental handicap accompanied by serious physical disabilities. He is confined to a wheelchair, has limited use of one hand, is doubly incontinent and has no speech.

Apart from a three month spell in hospital, Iain has always lived at home. For the last five years, he has spent occasional weeks or weekends in the local hospital, the only place that 'will take him on'. With the exception of these odd breaks, and the time he spends at the special care unit, Iain's parents provide continual care. 'Physically he can't do anything at all for himself. He has to be fed and changed and lifted. So we totally care for him, completely.'

Iain's parents have very mixed feelings about continuing to care for their son at home. On the one hand, they are very conscious of the demands, both physical and psychological that it involves. 'Psychologically you feel terribly tied – even if you can go out, say, and leave someone sitting here ... Wherever you go you know you must get back ... For the first 16 or 17 years we never slept totally through the night. You were always up and down to him, two, three depending on how he was, sometime five, six times a night ... So you were physically tired, which meant it put a strain on your relationship, obviously ... You've got to time everything ... by having to sort of think about "is it time to give him a drink? ... is he tired? ... or is his bib wet and you need to change him?" ... it's just what next?

'The other weekend the other two children were in a play ...

and Iain had gone into care for the weekend ... We had a whole day – two of us – we went to Durham – walked round, lunch, walked round – never done it before ... I can't honestly remember a day when we've had just a day out ... As the other children get older, you expect a bit of freedom like everyone else and it's only then that you begin to think that you may never get it. Your other friends are free to go out and your teenage children can look after themselves, but you're different as a family ... You realise just how little freedom you have ... Can't go out and leave the house ... couldn't just go out for a drink.'

Despite the restrictions which caring for Iain place on their lives, his parents, at present, would not contemplate any different arrangement. The reasons for this are numerous. 'We enjoy having him here ... we want him around ... He's so affectionate ... He reacts to people in such a big way ... that's the joy ... And he is so vulnerable ... He's so much better off here ... If I thought he would really like it and enjoy it you'd be quite happy to let him go. Then you wouldn't feel guilty ... And also when other people are having to do your work ... they say you shouldn't worry ... but he's our child ... The only place (that could take him) is the hospital because they say there is no home that could cope physically with his sort of special needs ... At home he's so much better off than hospital care ... he's sufficiently aware to want a family atmosphere.' Although Iain's parents would desperately like to use short-term care more often, they see the present situation continuing for some time 'Our views are just, you know, wait and see ... you know you are getting older obviously. You don't know what's going to happen. You just hope ...'

For most people, the idea of having a mentally handicapped child or adult at home conjures up an immediate image of considerable stress. The frustration of constantly coping with someone who cannot live independently, the sheer exhaustion created by a lot of extra work and possible loss of sleep, the lack of opportunity to go away and relax all add up to a vision of a stressful and unrewarding daily toil. Certainly, this image is quite appropriate in a large number of families. Where the handicap is more severe, of course, the problems are more acute; frequent epileptic fits, for instance, create the stress of being 'constantly on the alert'. But even where the handicap is not especially severe, parents speak of the sense of being 'confined', of 'living in one circle' and, more generally, 'your life is never your own', While such restrictions are normal for all parents with babies or young children, they are quite abnormal and harder to accept as children grow into adulthood. They are also abnormal for parents of retirement age. A number of parents had experienced periods of poor mental health arising from the strain, including one with a mental breakdown. Marital stress was also not at all uncommon.

But it is important to emphasise that this is only one part of the story. Although looking after a handicapped son or daughter does impose considerable burdens on families, there are many compensating rewards. The ordinary activities of caring are commonly carried out in the context of family warmth; there is the companionship, common interests, shared humour and general intimacy which can occur within any family. On a deeper level, the positive side is hard to describe without recourse to the overused but overriding sentiment of 'love'. For these families, it appeared that the parent-child bond became strengthened over time, deepened by the many years of constant care and attention and by the added vulnerability arising from a handicap.

All the parents under discussion here are caring for adult sons and daughters, yet their relations are in many ways more akin to those of parents with young children. In the absence of the normal period of emotional distancing at adolescence, parent-child relations seem to become more – rather than less – close. At a time when most parents would be turning their attention to other interests, the activities of the parents with a handicapped son or daughter are still closely bound within the family. Indeed, some parents commented on the fact that the presence in the home of a young person, with the interests common to young people, kept them feeling 'young' as well as strongly needed. The result is an adult son or daughter who is 'one of us', a family that is a trio instead of a couple. Doing things together, going places together, becomes the norm, a 'way of life'.

Perhaps surprisingly, parents' feelings of being burdened did not seem to increase with their own age. One might expect parents to cope quite adequately while in their fifties and sixties, but to find their situation increasingly difficult as they themselves became elderly. Our evidence does not confirm such a hypothesis. Even very elderly parents, and we interviewed several aged 75 or over, did not seem unduly burdened by their situation. Parents whose own health was a source of concern were naturally somewhat anxious, but did not feel that they were more burdened because of their son or daughter's presence in the household. The parents who seemed under greatest stress were those whose handicapped son or daughter seemed most stressful – whether violent, subject to frequent fits or simply constantly depressed and uncommunicative.

It must be emphasised that families with handicapped adults have been living with their situation for some time. They have had many years in which to come to terms with their restricted circumstances and accept their son's or daughter's limitations. They have organised their lives around their handicapped child, so that the restrictions he or she imposes are largely taken for granted. Furthermore, they are to some extent self-selected, inasmuch as many of those for whom the burden was too great would have taken action (where possible) before this point. It is probably also the case that handicapped adults are, on average, less stressful than handicapped children and, indeed, many parents spoke of the heavier burdens experienced when their son or daughter was younger.

Fostering independence

While our study was concerned with the issue of a move from home, this itself cannot be discussed in isolation from the question of the development of independence. This has two quite distinct meanings: on the one hand, it refers to a person's ability to carry out certain tasks without assistance; on the other, it refers to the disengagement of a person from emotional dependence on his or her parents. All children need to develop both forms of independence and most parents try to enable this to happen gradually. Where the child has a mental handicap, the process is more prolonged and parents may have to take more of a lead.

SUSAN is 20 and lives with her two parents (aged 56 and 45) and younger brother. She is severely mentally handicapped, epileptic and has a tendency to self mutilation. She is an articulate determined young woman who is now able to do most things for herself.

Her mother is particularly concerned to develop Susan's independence and constantly encourages her to do new things. 'I want her to be independent ... particularly for her self-confidence because that's what she totally lacks. When she does show signs of wanting to be independent we'll do everything we can. For instance, a few weeks ago she said "I want to go the library on my own" ... Now that means crossing a very busy main road. She wanted to do it ... so I tailed her on the other side of the road. There's no way I could let her go on her own but she didn't know I was there.'

Her mother admits that it has taken a considerable amount of patience to teach Susan to be more self reliant. There have been many times when it would have been much easier not to persevere. In this respect, there has been some conflict between Susan's parents 'This is where my husband and I disagree ... I'll want to pursue it and try and make her do it on her own and he opts for the easy option ... but it's not to her benefit.' Susan's father thinks that trying to develop independence is right only up to a point. 'We differ on what extreme we go to to obtain that end. If she feels she's being left alone to do something which she doesn't want to do ... it will upset her ... I think "that's enough" ... if she's really getting upset then I will give in.'

Despite this disagreement, Susan's parents are united in the view that her needs are paramount and that, for the time being, she should stay with them at home. Her mother, however, is much more concerned about the long-term problem and, with some encouragement, would quite possibly begin to prepare for a move from home. 'If suppose suddenly there was a big change in her and they said look there's a place and she can come and live there permanently. If that happened next year, then I'd say "go", but it'd crease me. But if it made her independent and created her own little life for her for the future, then you'd have to do it ... It would be hard to let her go, but I would do it because I want the best for her.' Her father is less inclined to think about the future while there are still several years ahead when she can stay at home. 'My view is that ... let's not worry about what's going to happen when she leaves home. I don't see the point in worrying ... about things that have yet to happen which may never happen.'

The matter of developing their son or daughter's skills was one with which most parents were very concerned. It was also one about which a considerable sense of guilt was expressed. As one father said 'the biggest enemies mentally handicapped people have got are their own parents . . . [they're] over-protective. Won't let them go, won't let them make their own mistakes.' The problem arises, essentially, because it is almost always easier to carry out a task for a handicapped person than to allow him to struggle but learn. Nonetheless, parents were very aware of their children's need to learn how to cope to the best of their abilities, from having a bath to going out alone.

The issue of teaching people with mental handicaps to care for themselves is complicated, of course, by the problem of risk. While a large number of parents feel they over-protect their son or daughter, the fear of harm is also a real one. This arises both in the home, for instance with respect to cooking, and outside it, with worries about both traffic and strangers. A few parents recounted stories of an actual or near-disaster, but for the most part it was not something they had experienced. Instead, the fear of subjecting their child to harm provided a significant brake to their concern to enable him or her to develop.

The need to untie the strings of emotional involvement with their sons and daughters is expressed much less frequently by parents. This may be partly because it is less easy to identify how this should be done, compared to the development of practical skills. In addition, however, many were not themselves concerned to do this any earlier than necessary. Mothers in particular spoke of being 'over-possessive' of their children and some clearly enjoyed having 'a baby all my life'. Nonetheless, a number of parents were highly concerned about the need to disengage themselves for their son's or daughter's own good. They spoke of the need to encourage other relationships, both among peers and others such as hostel staff.

These processes, it will be noted, have their parallel in the relationships of parents with their non-handicapped grown children. The differences arise in two important ways. First, there is the lack of initiative from the handicapped son or daughter to break away from the parent. This is probably partly due to a passivity developed over the years and partly to a lack of opportunity to do anything else. Most parents do not have to think about these problems, as they are thrust on them, often quite forcibly. Their growing children not only try to take on activities involving physical independence but also find their own friends and relationships. Indeed, the decision to marry and form a new family is often seen to constitute the key indicator of full maturity and independence. In the case of handicapped sons and daughters, in contrast, it is the parents who have to make the running. It is not an easy task.

A second difference concerns the value which parents place on their children achieving maturity. However difficult the process of letting go, parents will usually take some pride in watching their children grow up and become adult. They will recognise the need for their children to express preferences, make their own decisions and eventually take independent action. Indeed, the lack of such behaviour among young adults might well be the cause of some concern to parents. For mentally handicapped young people, in contrast, there is almost inevitably a lower parental expectation of developing maturity. Perhaps as a consequence, similar behaviours do not appear to be valued in a similar way. Parents may fail to acknowledge – or even dismiss – any adult choices the handicapped person wishes to make, for instance, having a boyfriend or girlfriend or wanting 'a place of my own'. While the parents may well have reason to see these choices as inappropriate, the process does little to encourage the mentally handicapped person to develop independence of thought or action.

Attitudes to making the break

Parents' views on making the break from their son or daughter tend to be highly complex. There are a number of different concerns and these affect parents in different ways. As we illustrated above with three individual families, there are some parents who are seeking an alternative home for their son or daughter, some who cannot contemplate a move at all and some who are deeply ambivalent about this decision. These three positions need to be considered in some detail.

First, some parents are concerned to find a place for their son or daughter outside their home. For a few, this is because they feel it is in their son's or daughter's interest to develop independence from the family. For rather more, however, the situation is more pressing. These include some who feel that, because of their own age, health or other circumstances, it would be best for their son or daughter to move out soon. Others have found that the accumulating stress has become too great for them and they need some time for themselves. Among these parents are those whose son's or daughter's handicap is

MATTHEW is 36 and mildly handicapped as the result of an accident at birth. He can read, write, has an excellent memory and is a keen musician. According to his parents, 'he's definitely a character. He's an extrovert in every sense of the word, with a tremendous sense of humour.'

Matthew's parents are in their 70s and his father, after a major operation, is now in very poor health. They have a very close relationship with Matthew and both are quite devoted to him. They feel they are over-protective with Matthew, but there is clearly a real dilemma. 'Being a parent you automatically do for them – you can't help it. Partly you want them to look good all the time and partly it's because you just want to keep on doing things for them.' Again they are aware that they could have done more to encourage Matthew to be independent. 'You want him to be independent but at the same time it's difficult to put over this independence, and you are forced to do things that *they* want you to do although you know you shouldn't do it. For example, he won't tie his shoe laces so in the end we finally buy shoes for him that have *no* laces – slip-on shoes and that gets over the problem. Well it's wrong.'

Matthew's mother admits to it having been a wrench when her three older sons left home but saw it as a natural progression. With Matthew it's different. 'I always thought I'd look after him as long as I could ... I'd keep myself in good health and look after him, and I have done.' But at the same time, both parents are aware that it's not necessarily the best thing for Matthew. 'I mean, that's obvious ... you think you're doing the best for them but deep down you know damn well he'd have been better off in a place where they'd have given him a thorough education – but would they have looked after him? Would they have given him a home life?'

Because of his father's illness, Matthew's parents have begun very reluctantly to consider the issue of his move from home. They have written for information about village communities and asked around about the local hostels. They feel that life in the 'village system' would be best for him because of the small, family-type living arrangements. But if a place became available, to go ... 'a lot's dependent on Matthew – if he puts his foot down and doesn't want to go – I can't go against that, can I?'

Matthew's parents think it is most likely that he will eventually go to live in one of the local hostels. They think that when the time comes 'he will probably adapt OK ... he's very realistic.' Deep down, his father knows that they should be taking some steps to effect a move in the very near future. 'We're not youngsters any more ... [if he agreed to try to live elsewhere] I would be happy; it would be so terribly important for him.' But his mother is less sure that she could ever part with Matthew. 'He's part and parcel of my life ... my life is Matthew. It has been for such a long time that I can't visualise it any other way. And I don't think I would want to.'

most severe. They tend to carry the heaviest burden in the home and are most likely to be under the greatest stress. They are also the ones who have the most difficulty in finding either any place at all, or any place besides a hospital, which will accept their son or daughter. As we discuss below, there tends to be more provision available for people with mild handicaps. A problem therefore arises for families with severely handicapped members, as they may have both a heavier demand for – and smaller supply of – alternative provision.

Second, some parents are not in any way looking for alternative provision; these tend to be more diverse. They include some parents who have come to live with their situation, whatever its considerable drawbacks, and some for whom it provides a high level of what we would call 'parental joy'. Some are still quite young and have not yet begun to address the question of any need for their son or daughter to leave home. Others, however, are very elderly but have come to rely on their son or daughter for company and a sense of interest in life. Many argue that caring for their own offspring is a natural responsibility of a parent, and where a handicap exists, should continue until the parent can no longer cope. Others, however, are anxious to express the enormous pleasure they gain from having their son or daughter at home. In addition, many feel strongly that it is their son's or daughter's strong wish to remain at home.

Third, there are large numbers of parents who are highly ambivalent about the whole question of a move from home. They too, tend to have a strong bond of affection for their son or daughter and a reluctance to see him or her leave their household. But they are also aware that it may be in their son's or daughter's interest to move on, either because they are already elderly or because a more independent life is possible and desirable. The question of the move from home catches these parents on the horns of a dilemma: they know that eventually some provision will need to be made but they cannot contemplate the idea of seeing them go with equanimity. As one widowed father put it: 'I'm torn between the devil and the deep blue sea. I want to see him settled before anything happens to me, but I don't want to see him go away before that time.'

It is clear that large numbers of parents feel that they either want to – or ought to – care for their son or daughter at home for an extended period of time. This view tends to be strongly reinforced by messages, often quite explicit, received from key outsiders, including doctors and social workers as well as friends and relatives. These parents come to believe that they are the 'good' ones, willing to devote their lives to a son or daughter with a mental handicap, compared to others who 'put them away'. Many have been told at one time or another that caring is their responsibility, which they should not try to impose on others. Those with bad experiences of care outside the home, in particular, often feel that no one will ever look after their son or daughter like they will. The effect of a bad experience – or even a strong comment from someone in authority – seems to endure over many years.

Such concern is also reinforced by the lack of pressure from 'below', the infrequent initiative of a son or daughter to propose a move out. This is not invariably the case. Some mentally handicapped people had suggested a stay in the local hostel as a trial separation, and some who had done so had raised the possibility of turning such stays into longer-term arrangements. But on the whole, parents of mentally handicapped sons and daughters are not subject to the same pressure as other parents, wherein the initiative from the post-adolescent child to move on is very strong. Certainly, the ability of the son or daughter to put into practice any intention in this respect is much more limited.

It must also be added that we found many parents isolated and unable to explore these (and other problems) with anyone. Many had little support from family and friends; even those who had some help from these sources found that it impinged relatively little on their daily lives. Furthermore, and much more worrying from a policy point of view, many parents also had little support from professional sources. There was too commonly a high level of distrust of social workers, viewed as having little interest in their problems and little competence in dealing with them. Much of this seemed to arise from the infrequency with which they saw a social worker; indeed, it would be difficult to say whether many of the families 'had' a social worker at all. In addition, however, the problem of 'battle-worn parents', as one mother termed them, getting a social worker 'talking to you as though they know it all' seems very great.

One possibly surprising conclusion of our study is that the degree to which parents felt they were given general support by others did not seem to affect their disposition to seek alternative care. Of course, those who had a lot of help from family, neighbours or from professional sources were grateful for it and, conversely, those who had to cope in its absence felt some irritation about their isolation. Comments on public attitudes to mental handicap, as reflected in the help they received in their local area, were common; a number of

SIMON is 22 years old, the third in a family of four. He is the only one now living at home, although his younger sister is home during college holidays. His father works full-time and his mother part-time while Simon attends a local day centre.

Simon is severely autistic, has no speech and is behaviourally very disturbed. His mood fluctuates to extremes. Sometimes he's 'really quite responsive and active, on the ball. At others he becomes withdrawn and passive, or again he will become hyperactive and fling himself around and knock into things. He's prone to temper tantrums during which he bites his own hands quite savagely.'

Simon's parents find his extremes of behaviour very difficult to cope with. He is physically strong and therefore impossible to restrain when he is disturbed. When he is inert and withdrawn they worry, knowing that these phases usually end in a burst of frenzy and unhappiness. Both parents find coping with Simon very stressful. They have no support from other family members or friends and because of Simon's unpredictable and sometimes violent behaviour they feel they cannot leave him with a 'sitter'. They talk also of the complete lack of help or support from social workers.

Simon has lived away from home in the past. When he was six he spent two years as a weekly boarder at a special school. This arrangement broke down due to staffing problems and Simon's own health. He has been on holidays organised by Mencap and in the last five years has been going into short-term care on a regular basis for a weekend a month. This arrangement has also broken down following the loss of a 'very competent male deputy' and the inability of the remaining staff to cope with Simon. This latest rejection has been a colossal blow to Simon's parents for whom these short periods of respite were vitally important. They are now beginning to doubt their ability to cope.

If there was adequate short-term care (at least once a month, preferably every two weeks) for Simon, his parents would be happy to keep him at home for a few more years. However, his father feels that by the time he and his wife are in their middle 50s he would prefer to have Simon living away, 'provided it was perfectly marvellous and he was very happy'.

What they would like ideally for Simon would be a small group living together – perhaps five or six – in a comfortable home with good, caring staff. They are sure that where larger numbers live together there is a danger of institutionalisation. 'However well meaning people are, the sheer size of the thing turns it into an institution rather than a group ...' They do not want Simon to be cared for by his siblings, feeling that this would be 'a terribly unfair imposition'.

Simon's parents, with others, have formed a trust to raise money to set up a home. This has taken up an enormous amount of their time and energy. They are hopeful that they will be successful in their fund-raising, but at the same time feel bitter about the lack of help from the authorities. 'We're having to raise our own money ... fight all sorts of battles for our children and it's the unfairest thing in the world in a sense to impose on people who are absolutely fighting for survival anyway every day of their lives.'

parents expressed considerable anger at the lack of sympathy for or understanding of their situation. But whether supported or isolated, parents' wish to keep their son or daughter at home (or not) rarely seemed to revolve on this issue.

Preparing for and undergoing a move

Most of the families with whom our research was concerned were not imminently seeking a move. Some, indeed, were so unwilling to think about the subject at all that any discussions about it were clearly avoided. Nonetheless, a few were beginning to prepare for this eventuality, a few had undergone the move and a few, with sons and daughters back at home, had done so unsuccessfully. The experience of all of these groups is important for our study.

Preparing for a break is generally a slow process, requiring both the parents and their son or daughter to become accustomed to the idea of change and separation. One key aspect of this process is the development of increasing independence, discussed above. But another important component is the use of trial separations as a means of experiencing periods without each other. The majority of families in our study had used short-term care at some time, often to give the parents a break. Most said they found the separation highly distressing, especially on the first one or two occasions. They were unable to relax, worrying terribly about their son or daughter; a number said they felt 'lost' in his or her absence. Where the use of short-term care was fairly frequent, however, parents found they were able to accept it more easily and, eventually, begin to relax and enjoy the 'freedom'. The initial doubts and anxieties were replaced by a sense of confidence that their son or daughter was all right. Indeed, in some cases it was the first step to serious contemplation of longer-term care.

This conclusion, that experience of short-term care can have a significant impact on parents' willingness to consider alternative care long-term, needs some underlining. Arrangements for respite care are frequently advocated as a means of easing the burdens of hard-pressed families, helping them to keep their son or daughter at home for the longest possible time. But we are suggesting that the use of short-term care, particularly on an extended basis, may well have exactly the opposite effect. Parents' initial reluctance to contemplate a move from home is slowly turned into an appreciation that their son or daughter could have a life elsewhere and, indeed, might even be happy there. This takes time, or course, and the right conditions, but it is nonetheless a very important finding.

More generally, we found that the planning and preparing process often requires some catalyst to get it under way. Given the commonly expressed need to 'live from day to day', a kind of inertia sets in whereby parents do not naturally turn their attention to difficult and distressing questions. Furthermore, many are reluctant to appear in any way to be pushing their son or daughter out of the house. In some families, the catalyst role was played by a concerned sibling. In others, emphasised especially by those whose son or daughter had left home, it was played by a sensitive and sympathetic social worker. The parents needed considerable time to digest the idea that their son or daughter might leave home, explore its implications and consider the practicalities. Most commonly, however, the need for this extra 'push' was highlighted by its absence. Parents found no one raising the issue with them, while stressing to us their wish not to have to initiate this move, not to ask but *to be asked* if the time was yet right.

Another important aspect of the preparation process is the attempt to hold some discussion with the son or daughter about the need for a move. Some, of course, could not do so because the sons and daughters literally had no speech and a number felt that they would not be capable of understanding the issues. Nonetheless, a number of parents had tried to discuss the question on the grounds that it was right for them to do so. Few found it easy, as they were anxious not to make their son or daughter feel unwanted. Some of those with other children said that it helped to make a comparison with the brother or sister leaving home.

Included in our study were a few families where an attempt had been made to undergo the move, but it had not worked out and the son or daughter was back at home. In two cases, the problem arose from an unwillingness of the sons to stay in the chosen hostel, combined with an unwillingness of the parents to force hostel care onto them. In another, a hospital placement was lost due to the policy of reducing the numbers in hospital care and the parents were not happy with the alternative provision offered. In two others, parents chose to remove their son or daughter from hospital care because they found it unsatisfactory; in yet another, the move to home was prompted by a social worker who felt that the alternative care was not in the son's best interest. Parents' comments on the provison experienced are offered below, but first, what lessons can be drawn from these experiences?

We found that there is sometimes a fairly stark picture of how changes in a mentally handicapped person's living arrangements can occur. Placements are not always made with sufficient care, nor with sufficient consultation, preparation and counselling. Decisions may be made more on grounds of what is available, rather than what is in the long-term interest of the handicapped person, when he or she is 'being moved'. For anyone, moves are inevitably unsettling – even more so when they are abrupt and unplanned. For a handicapped person, who may have no say in the matter and who may be less able to anticipate the implications of any change, this is a particularly difficult problem. It is not surprising, for instance, that a trial move to a hostel proves unsuccessful, when it is without any apparent preparation, has no sustained support and perhaps was not an ideal choice in the first place. But parents, too, need help – not only at the time when they are preparing for the move but also much earlier. They need much more information about available provision, so they know what to expect for their son or daughter. This should not only help them to decide where he or she should go but also ease their anxieties during the time of transition.

But not all moves are unsuccessful. We also spoke to some parents whose son or daughter had successfully settled into a local hostel. Their experience is particularly germane to this study. Although they stressed the importance of the preparations towards the move, the experience of parting from their son or daughter was almost invariably a shattering one. None had taken this decision at all easily; it had generally arisen because of new available provision and the fear that a similar place would not be offered for a long time. Yet they tended to be highly ambivalent about this 'terrible decision' as one mother called it. The period preceding the move was particularly difficult, since it was a time in which the decision could be reviewed and, in principle, reversed. Several told us how they hoped the decision would be taken out of their hands, by the place becoming suddenly unavailable.

While moving day was generally traumatic, it was the period immediately after the move which parents found most distressing. Several likened it to a period of bereavement, partly in their own sense of loss but more in other people's reactions: 'people don't ask you about it; they don't like to approach the subject because of upsetting you'. Just having an empty house and no one to cook for could leave a terrible gap in what had previously been a very busy life. This was a time in which parents greatly welcomed help from outside. An interest from their social worker in their well-being, as well as that of their son or daughter, was especially welcome. Some found it enormously helpful to talk to other parents in the same situation.

After some time, however, these parents felt they began to cope and, to their own surprise, to relax. This was helped by keeping in frequent touch with their son or daughter, whether by visiting the hostel or by having him or her home for a weekend. They expressed few doubts that from their son's or daughter's point of view, the decision to move on had been the right one. In some cases, considerable strides had been made in the development of independence. Furthermore, parents could see that their child had settled into a new 'home'. For instance, one father spoke of his daughter returning to her hostel after a weekend visit, having thanked him for a lovely time. 'She turns to me and says "I'm going to my room now, Dad" ... and she's away. She's quite happy and that's great. That's all I need.'

Alternatives to home

The desired alternatives

Parents hold remarkably clear and consistent views about what any future living arrangements for their son or daughter should be like. It should be a home – not an institution, not a hostel, not a boarding house, but a home. In parents' terms this means providing a warm, caring environment, a sense of security in both physical and emotional terms, and a reasonable degree of permanency. These requirements are universal, permeate all discussion of possible alternatives, and are the major determinants of the forms of care required.

There is more divergence of view about the exact form any provision should take, but small, staffed, 'family style' houses or units are very much on the agenda. Five rather different models of care are commonly advocated:

Family-style homes are a form of care which many parents want to see available. Essentially, these should be small, with perhaps six to eight residents, and have one or two staff members living in. The residents would live as a 'family', have their own things around them and do as much as possible in the household. It is commonly envisaged that the accommodation would be in ordinary housing and would provide a permanent home for the residents.

MARK is 24 and has Down's syndrome. He is a quiet, capable young man and has a gentle and affectionate nature. His mother, now aged 65, describes him as a 'much wanted and greatly loved son' being the only child of a second marriage. Mark's father, who was also very close to Mark, died suddenly when he was 16.

Shortly after his father's death, Mark's mother heard of another widowed mother living locally who had collapsed and died. This mother, too, had a mentally handicapped son, who had been found alone, three days later, with his mother's body. Mark's mother began to worry. She was living in a city where 'nobody would notice if the curtains stayed drawn', her husband had died suddenly and so had this other mother. So although in good health, the thought of dying began to prey on her mind. 'I used to think, if I could get Mark into care I could die happily.'

When she heard about a new hostel in her neighbourhood, she made the decision. 'I suddenly burned my bridges ...' Mark's name was put down and they made several visits to familiarise themselves with the place and the staff. There followed a period of doubt and stress for Mark's mother – compounded by a postponement for six months of the date of Mark's departure from home. To Mark she made it sound exciting. 'I used to say, "it's a lovely room Mark, won't it be lovely" and he used to say, "Yes", bless his heart. But I didn't want to think about it. I ached, I really ached. You cannot prepare yourself for the break. You have to wait till it happens.'

For Mark, the actual move was not traumatic. He liked the hostel staff and was excited about unpacking his things in his new room; but for his mother, it was 'desperate. I was full of grief and wanted to cry. But I couldn't let Mark see – he couldn't bear to see me cry.' She spoke of the strong sense of finality and of resentment – 'that life had made it that I had to let Mark go'. At the staff's request, she didn't visit for three weeks. During this time she felt overwhelmingly sad, but when she did visit she found Mark happy and settled and when, after ten minutes he said it was time for her to go, she was pleased; '. . . this was indicative to me that he was happy'.

But adjusting wasn't easy. The intensity with which she missed Mark had to be weighed against the relief of knowing that he was happy and settled. 'It was so conflicting, your emotions are so at variance. One part of you is happy for your child, the other part is "oh I miss him, I love him, I need him". I only realised later that I needed Mark more than he needed me. If you're honest about it you do as you get older – you need someone. And I'm a touching person. I missed contact. I could cuddle Mark – kiss the back of his neck. So I missed this very vital thing for me – the touch.'

The hostel has provision for 24 residents. Mark's mother feels this is too many and hopes it will be converted into smaller units. The staff are 'dedicated, hard working, loving and caring'. Parents are made to feel very much part of their son's or daughter's life. Mark is learning to cook and has a social life he didn't have before. He has become a more rounded person. 'He's a personality now. He wasn't – he was my little boy . . . It's made me realise that I didn't really treat him like an adult.'

Mark's mother is happy now and enjoys being able to go away sometimes. Above all she has a sense of profound relief knowing that 'if anything happens to me, Mark is all right – and that's worth all the grief, all the tears, all the sadness.'

Village communities are also popular among parents. The model envisaged tends to be based on existing schemes, such as that run by the Home Farm Trust. In parents' terms, they are viewed as communities in rural areas, where residents have all of their activities on one site; for instance, work, leisure, housing and shops. Although they may be fairly large over all, the living arrangements should comprise small units in houses in the community grounds.

Hostel-based units are sought by some parents, close in concept to those currently provided by local authorities. While the hostels themselves may be fairly large (20 to 40 residents), parents envisage that the residents would be grouped into smaller units, of up to, say, ten people. The hostels should be fully staffed, although residents should be encouraged to do as much as they can for themselves. This form of hostel is seen clearly to be based in the community, near to all amenities.

Sheltered accommodation is advocated by some parents, based on existing models of housing for elderly people. Residents would live in a complex of housing and would largely look after themselves, doing their own cooking, shopping, housework and so forth. A resident warden in the complex would keep an eye on residents and deal with emergencies. Again, the complex should be sited among ordinary housing, although it might need to be purpose-built.

Group homes are advocated by relatively few parents, except in a sheltered environment. Some, however, like the idea of three or four mentally handicapped people living together in ordinary accommodation. Although parents do not envisage resident staff in such circumstances, they tend to feel that regular supervision and support, probably on a daily basis, would be essential.

When parents look afresh at their preferences, it is notable that neither hospital care nor more individualised forms of care, such as lodgings and family placement schemes, are spontaneously mentioned. In the case of hospital care, parents generally hold strongly negative attitudes. In the case of individual schemes, in contrast, the key problem is lack of knowledge, that is, parents are largely unaware of the existence of such schemes.

Not surprisingly, parents' requirements for their son or daughter in part reflected his or her abilities. Thus, parents whose son or daughter had a severe handicap were more likely to express the need for high staffing levels, individual care and protection; those whose son's or daughter's handicap was less severe were often more concerned to maintain or develop some independence. It would be fair to say, however, that the correspondence between parental requirements and their son or daughter's abilities was by no means exact.

In this context, it is important to note one issue on which parents were much more deeply divided. This is 'training for independence' now practised in many hostels and residential homes. Although a few parents felt their son or daughter could be trained to live fairly independently, this view was very much a minority one. More commonly, parents argued that while mentally handicapped people should be encouraged to do as much as possible for themselves, this should not be taken too far with 'people expecting too much'. Some parents, indeed, took a more extreme view, suggesting that their son or daughter was not capable of doing anything for him or herself. In consequence, they argued, it was unrealistic to undertake any kind of rehabilitative effort, whatever the environment. This concern created a major deterrant for some parents to using existing forms of provision. Even where this was not the case, it was clearly a matter of real anxiety.

Some families were not especially concerned to explore the formal provision available, as they viewed the care of their son or daughter to be solely a family matter. It was their assumption that the task of looking after the handicapped person would pass on to a sister or brother when they were no longer able to cope. Some had clearly established this plan with the relevant sibling. Others indicated that they felt the sibling would take over, although they had not explicitly discussed the issue. Raising the subject was clearly difficult and parents emphasised they 'did not like to press'. Most parents, however, felt strongly that it would not be fair for the sibling to be asked to take on the responsibility.

Views on existing provision

In general, there was a sizeable gap between what parents would like for their son or daughter and what is actually available. Despite this fact, many parents were not over-critical of what they had seen. Indeed, among those whose son or daughter had a mild handicap, opinion was in the main quite positive about the forms of care experienced, outside of hospital. The features that pleased parents varied but 'well trained staff', 'personal attention', 'lots of things to do', 'having their own room', a 'bright and clean' environment and 'an encouragment to do things for themselves' all received favourable mention. The principal reservations concerned the level of supervision ('they didn't make sure he changed his clothes'), including criticisms and worries about understaffing.

The parents of more severely handicapped sons or daughters were generally much less satisfied. Indeed, many had very serious reservations about the care experienced. Among those whose son or daughter had been in hospital care, the principal criticisms concerned the lack of personal attention, affection and stimulation for the residents. Those whose son or daughter had experience of a hostel, in contrast, were more critical of the level of staffing; they were often concerned that too little supervision was available. These reservations had made some parents reluctant to seek short-term care other than on the very odd occasion. Although some parents were relatively happy about the local hostel provision for their severely handicapped son or daughter, they saw it as only suitable for very short-term care.

There was a sizeable group of parents whose son or daughter had no experience of any other from of care (43 per cent in the southern area, 55 per cent in the northern area). Even higher proportions had had no recent experience (that is, within the last five years) and this was particularly the case for people in their 30s and 40s, whose parents were now quite elderly. Perhaps surprisingly, this reticence to use a formal care arrangement, even for short stay, did not seem to stem from an overt dislike of what was available. Indeed, those who had any knowledge of local provision were not unimpressed by what they had seen or heard reported. What deterred them, it seems, was that other arrangements had never been essential and they had been given little encouragement to use them. This may be particularly an issue with respect to older parents.

Knowledge of other provision

Parents' knowledge of the care arrangements available locally was, to say the least, patchy. Although some parents had a comprehensive picture, for instance arising from active involvement in a local voluntary group, this was very rare. It was much more common to find parents with some knowledge of one particular arrangement, often used for short-term care, combined with vague impressions of other provision. These impressions may have been obtained through contact with social workers or voluntary agencies or simply from hearsay. Yet other parents, again a minority, had no idea at all of what existed locally. In the main, these were parents who had no intention of their son or daughter moving to any formal provision, at least while they were alive, and therefore saw no reason to find out about it.

Information about provision outside the local area came through a variety of sources, but the media, voluntary groups and simple networking between parents were obviously important means. Attention appeared to be more focussed on specialised forms of care, such as schemes provided by particular trusts or foundations (for example, village communities, Steiner homes) rather than on new or developing forms of statutory provision. This point was particularly highlighted when we sought parents' views on different types of scheme, including those based on the 'core and cluster' concept. With one exception, the parents attending group discussions had never heard of the term nor any of its inherent ideas. When these were discussed, the response was generally favourable, particularly to any variety of provision which took some account of individual needs. Parents' interest was very evident and they clearly would have welcomed further details and discussion. Although it is difficult to know where responsibility lies, the need for greater dissemination of information is evident.

JUDITH is 43 and lives with her mother (aged 68) and father (aged 72). She is able to do everything for herself, can read and write and is very talented at sewing and knitting. She is quite independent, dislikes being confined and goes out a lot on her own. In her mother's view, Judith is not really mentally handicapped: 'she's just very slow in what she decides to do'.

Judith's mother has devoted her life to caring for her daughter and their lives have become closely bound together. She is now highly dependent on Judith for companionship and emotional support. Although Judith's father lives with them, he leads a very separate life and, according to her mother, has never given her any support. 'I've never had a husband I could talk to ... he's never helped ... When she needed so much care, there were only one to give it and that were me ... He just carried on with his own life ... If it hadn't been for Judith, I wouldn't have stopped with him two minutes ... I've put up with it for her because I didn't want her to go from pillar to post ... I've not had a very grand life but she's made up for it. I've depended on her for company.'

Although Judith's mother is aware of her advancing years and is not in good health, she cannot imagine life without her daughter. 'I always thought she would want looking after ... always [thought of her] being at home. I've never wanted her to go anywhere else.' Although she thinks Judith might be quite happy in the local hostel – 'it's really lovely, it's like a little hotel' – she doesn't want her to leave home. 'Not while ever there's a home here ... While ever we live I don't want anybody else, no, she's part of us you see. She's part of home.'

Judith's mother hopes that her oldest daughter will look after Judith when she's 'gone' but discussion about this has been very limited. 'I think she'll [have her] – yes. They've always promised that when anything happens, to us ... they'd do whatever they can.' But, on the whole, Judith's mother does not think too closely about it. 'I never think about the future. I just live from day to day. I don't think you can plan for the future ... [even as far as Judith's concerned]. ... I just take it from day to day. ... I don't think she'll ever want ...'

IMPLICATIONS FOR POLICY

The pressures reviewed

While individual families must make the central decision about the move of a mentally handicapped person from home, local service providers need to know how best to plan and prepare for that move. As we have stressed throughout, there are two sets of issues: one is the nature of what is provided and the other the help which might be given to families to ease the process of transition.

This area of research does not give rise to easy solutions; the problems are not intractable but they are extremely difficult to overcome. There is a need for sensitive planning by those responsible for devising policies for people with mental handicaps as well as those involved in putting these policies into practice. To some extent, as well, there is a need for political will. This is particularly germane in this case, where so much policy attention has been given to a related – but competing – population. Before considering some specific policy recommendations, it may be useful to spell out exactly what the political pressures are in this area.

For well over a decade, successive governments have made the removal of mentally handicapped people from long-stay hospitals a principal policy concern. This has meant, in effect, that considerably more priority has been given to their needs than to those living at home with their families. The problem is much greater, however, than simply giving greater attention to one group rather than another. The two groups – those in hospitals and those in the family home – are actually in competition for many of the same resources. Not only might they both need the help of social workers and other professionals working in the field of mental handicap but the residential provision to which they might move may in some cases be one and the same. New hostels, new group homes, family placement schemes and so forth, can only accommodate so many people; if those people are former hospital residents, the population currently at home will not be able to find a place. Those moving from hospitals have the considerable advantage of additional resources directed to their needs. The pressure on current residential provision is obviously very great.

Following from this diagnosis, the current push to help the hospital population means that there is a considerable hidden incentive to keep the home-based population where they are. It is not simply that they are not a priority group; if they can be kept from competing for the same resources, the existing policy may prove more effective. Thus, a great deal of current interest in 'carers' might be seen to derive not simply from a concern to make their lives easier but from a very strong concern to enable them to continue in their caring role for as long as possible. Given that the hospital population has priority, this is perhaps understandable. Nonetheless, this context sets a difficult scene for any discussion about help to the home-based population.

This analysis may help to put into perspective the recent history of government policy on family care for handicapped people set out in the introductory section. The concern to enable them to remain at home, and the reluctance to recognise their potential interest in finding a new home, may be seen as part of a wider concern to avoid any extra pressures on existing residential provision. Nonetheless, it is clear that a policy of ignoring this problem entirely must soon founder. Parents of mentally handicapped people, no more than anyone else, do not live forever and provision must inevitably be made, later if not sooner. Indeed, official concern about this question is mounting. We therefore hope that our comments on the broader issues will be seen to be both timely and helpful.

Planning residential provision

It is very clear that there is a need for more residential provision for handicapped people. It is always easy for researchers to argue for more resources to be put in the direction of their particular interest, but we do not do so casually. It takes very little thought at all to realise that enormous pressures are building up on existing provision and that the situation cannot carry on indefinitely. Even considering solely the numbers of very elderly parents caring for handicapped sons and daughters on their own, it is evident that alternative places will need to be found. The policy of seeking the closure of mental handicap hospitals, whatever its desirability, has added to the problem by removing the principal traditional resource for handicapped people coming from the parental home. There is a growing need for further new provision to take its place.

There would, we feel, be enormous benefit from involving parents (as well as handicapped people themselves) in the planning of residential care. This already happens in some areas, with parents' groups represented on committees concerned with planning future provision. They need to be represented in more than a token way; as we have shown, they have many differing views arising from their differing circumstances. We would not argue that such views are the sole ones to be taken into account, but there is a wealth of practical experience which could usefully be fed into the system. Certainly, it is striking that parents seem to know what they want and that it is not necessarily highly expensive. These views need to be fed into the planning system on a regular basis over a period of years.

In terms of the forms of care required, our research on parents' perspectives leads us to argue for a wide range of residential provision. This should encompass not only various types of accommodation – individual flats and houses, clustered self-contained units, small staffed homes, family placements and so forth – but also different levels of services and resources. Such a range is important in order to accommodate the individual needs of people with mental handicaps and to provide some choice for families. The former point is frequently made, but the latter should be given due prominence.

Whatever the particular form, parents tend to seek a 'homely' environment for their son or daughter. This concern would receive much support from elsewhere. The need for more small-scale 'ordinary' homes for people with mental handicaps has been widely accepted. The problem is how this is to be achieved, given limited financial support and already over-extended resources. We would argue that part of the answer must lie in enabling people with mental handicaps to achieve a more independent form of living themselves. This will undoubtedly require a much greater infusion of training and support services than currently exists. But in the longer term, it should pay substantial dividends by providing many more unstaffed but secure and stable homes. It is also likely to require some re-examination of the roles of health and social services professionals, as the abilities of the handicapped population living independently develop over time. The response of these key professionals will be crucial.

We also feel there is a need for urgent consideration of the special circumstances of people with more severe handicaps. At present, there is minimal provision besides hospital for people who have a severe mental handicap or who suffer from serious physical disabilities or highly disturbed behaviour. The parents experience both a heavier burden in the home and a lower expectation of a possible move away, compared to parents whose son's or daughter's handicap is more mild. Any such provision will inevitably need a high level of staffing and the residents will require fairly intensive personal care when a move from home first occurs. Nonetheless, since hospital residence is restricted and largely deemed undesirable, some alternatives for people with special needs must be found.

In this context, it is useful to consider the potential for greater parental involvement in the direct development and organisation of residential care provision. In many areas of the country, groups of parents have been active in setting up, managing and supporting staffed or unstaffed homes. Usually, these activities have been channelled through an existing voluntary organisation such as Mencap or the Spastics Society, often in collaboration with a housing association. An earlier study by Jane Ritchie and Jill Keegan showed that partnerships between housing associations and voluntary organisations, if they are well directed and coordinated, can provide extremely successful and innovative forms of housing for mentally handicapped people.[1]

The question arises of whether such developments should be actively encouraged and facilitated by statutory authorities, for example, by providing information packs, specialist advisers, liaison officers and so forth. In our view, there are arguments both for and against. On the positive side, it is certainly the case that such partnerships extend both the amount and the range of provision available. It is also true that a strong and committed voluntary committee can provide the kind of organisation and inspiration needed to manage successful housing endeavours. On the negative side, there is a real problem that where there is weak organisation, unclear directives or poor coordination, the results can be highly unsatisfactory, if not disastrous, for the residents. It is also necessary to ask whether statutory authorities should encourage the very same people who provide care to spend their 'spare' time running other provision. Whatever the answer, it is clear that the statutory bodies must take seriously their responsibilities to provide support, information and counselling for residents and managers of voluntary based provision. There is also a need to consider how standards can best be monitored.

Helping parents

But in the matter of helping parents think about and, where desired, effect a move of a handicapped son or daughter from home, what conclusions can be drawn for policy? We must emphasise here that our study was able to consider only the views of the potential consumers of services and not those of the providers. In consequence, we cannot comment authoritatively on the problems and limitations from the service provision point of view. Further research is needed in this area, particularly on the constraints for field workers in social services departments in working with families. Our comments on the broad issues here, however, bear a striking resemblence to common sense. Essentially, what parents need is much more accessible information and much more support, provided over a more extensive period of time, than appears to exist at present. These need to be elaborated in some detail.

First, parents' needs for information on what is available are clearly not being met in a large number of cases. There are always some families who have searched out every corner and for whom additional information is not an issue. But most parents' knowledge of existing provision is sketchy and, as often as not, based on uncertain rumour. Few know what their local authority's policies are with respect to providing for people with mental handicaps, nor the range of provision available in the area or outside it.

Furthermore, parents' knowledge is often not very full. They may be aware that there is a hostel down the road, but have only the vaguest idea of conditions there, the nature of its staff, or the everyday life of the residents. These gaps are very important. One writer, herself a parent, put this very well:

> Few of us get the opportunity to look inside the various units, other than a brief conducted tour on open days, when the residents are out or out of mischief. This may show you the general taste in wallpaper ..., but it does not answer the real questions. What would life be like here for my son? What sort of people, with what attitudes and ideas would look after him ...? How would my daughter spend her evenings here? Would she be over-cossetted or under-supervised? ... Who will care?[2]

Parents also often do not appreciate that they do not 'lose' their son or daughter on a move into a hostel or other form of alternative care. They need to realise that they can visit him or her frequently in the new home and, indeed, have their son or daughter visit them for weekends. The contact retained by parents with their adult children is just as important in the case of mentally handicapped sons and daughters as in the case of non-handicapped people.

Of course, it can be argued that this information is there for the asking and that it is up to families to indicate an interest. This is true to an extent, although information could be made much more accessible. But to make such a case is to misunderstand the nature of the problem. Families need help in taking that first step of asking about this issue. It is so highly charged with feelings of guilt and betrayal, of 'putting away' their son or daughter, that many cannot take the necessary initiative. Some do not know even where to begin to ask, having had little attention from a social worker or any other official person. But, more commonly, they are reluctant to ask and want to be asked and encouraged to investigate what is available. They need to know that they will not be judged adversely for asking about provision and that their difficulties in doing so are at least in part understood.

There is also the key question of *when* the issue should be raised with parents. We have shown that the great majority of parents begin to worry about their son's or daughter's future at a very early stage, yet for the most part do not voice this concern until they are reaching a point when something needs to be done. The problem, however, only continues to grow; to quote the same writer again, it 'starts off as an occasional niggle at the back of your mind when the child is young and builds up, year by unrelenting year, to a constant crescendo of concern'.[3]

We believe that the issue of the move from home should be placed on the agenda with parents early and regularly. School-leaving age, representing a period of transition in any case, might be a useful time to begin. By the time parents are elderly, and their ideas and daily routine well set, it may be too late to have a strong impact. Many young parents will be uninterested in exploring the subject very thoroughly for some years; that is, of course, up to them. But having the question raised by others at an early stage 'sows the seeds', as one mother put it, and enables them to signal their own interest without embarrassment. Furthermore, it makes the subject seem more 'natural', helping to defuse some of the emotion so clearly attached to it.

There is a very sensitive but crucial issue for policy here: the need to break into what can virtually become a closed circle of increasing mutual dependency. This is at its strongest with elderly widowed parents who have middle-aged sons and daughters at home. They are the most unwilling to contemplate a move from home, although clearly the most at risk in terms of immediate need. The long-term answer is not to start at this point. We have noted that it is the younger parents, and often the apparently happiest couples, who are most able to think through this issue from their son's or daughter's point of view. This may be, as commonly asserted, a difference of generations. We suspect, however, that the differing views also arise because the parents are at separate points in the life cycle. The need to offer help when parents are still reasonably young cannot be overemphasised.

We suspect that many social workers are themselves reluctant to raise this subject, worried both about offending parents and about the awkwardness of forcing people to think about their own death. They must also have a concern about the paucity of provision available. Yet we have found that most parents are already highly tuned to the problem and able to discuss it with an impressive degree of dispassion. Parents are also, for the most part, able to explore the issue with a minimum of prompting, once it is accepted as a legitimate focus of discussion. What they need most is a ready ear.[4]

On a very practical level, it should not be difficult for authorities to put together a package of information for parents of handicapped people. This could include information on a wide variety of issues, but our interest here, of course, is in material on the move from home. This should cover information on local hostels and other residential provision in the area, the authority's policy on sponsorship and other sources of help and, finally, the ways in which parents can be assisted to think about – and prepare for – the move from home. At the very least, a file in local libraries with this information should not only be available but also widely publicised.

One example of a booklet for parents addressed specifically to this issue has come to our attention, although there may indeed be others. Prepared by Wolverhampton Metropolitan District Council, it derives from discussions with local parents and gives extensive consideration to the nature of local provision and how parents might be helped to prepare for it. It addresses a number of common worries, from the general, such as whether there are sufficient places, to the particular, such as whether young hostel staff can provide appropriate supervision.[5] It is written in a matter of fact manner and would appear to be useful model of the kind of publication to which parents could relate.

Parents' attention might also be drawn to a number of publications concerned to help them think about the future. Three are particularly appropriate to mention here. The different forms of residential care available are explored by Mary McCormack in *Away From Home.*

She takes a parent's view of a number of kinds of provision and is particularly concerned about arrangements for more severely handicapped people.[6] The development of independence, including advice on how to both foster and monitor it, is the focus of another book for parents entitled *Learning to Cope* by Edward Wheland and Barbara Speake.[7] A number of legal and financial issues facing parents with respect to the future are considered by Gerald Sanctuary in *After I'm Gone: what will happen to my handicapped child?* He also provides a useful discussion of the benefits and services available to parents and considers other relevant issues, such as the need to increase the capacity for independence.[8]

We should add that it is not solely written information that is needed. Parents also need to feel they can visit local provision to see what it is all about. There is an inevitable conflict in not trespassing on the privacy of residents, but visits during the day should not be a problem. Even better, parents need to be encouraged to let their son or daughter go to stay for regular periods, so that a real familiarity is established with the daily routine. Many people argue for the use of short-stay care 'to give parents a break', but this is not what is at issue here. The best arrangement is likely to be short but regular visits, so that each successive one becomes easier for both sides. We have shown how important this can prove for thinking about the long-term.

Another way in which parents could be given valuable support, mentioned by a number of parents who had undergone the move, is through involvement with a parents' support group. Many organisations for parents tend to be used more as a source of social activities for the handicapped son or daughter than a source of help for themselves. But when there is a very particular need, such as the crisis of seeing a son or daughter leave home, support groups can come into their own. The opportunity to talk to someone who has been – or is in the process of going – through the same experience can help enormously. It is only such parents who can say 'we know exactly how you are feeling, we know exactly what the problems are' and other parents tend to welcome such help.

The key issue here is the model which parents who have undergone the move can provide to other parents. This point was clearly made by one mother in our study whose son had left home, with enormous reluctance on her part: 'I'd love to go to some of the parents and let them see how happy I am now'. This was almost entirely due to the benefits to her son:

> First and foremost, it's your child and it's what happens to them and the benefits they accrue from going away. If you love your child, that is the most important thing to you and that helps you to come to terms with your own loneliness . . . My loneliness has gone . . . because I am happy about my son; that is the reward.

A difficult policy problem is raised by recommending greater parental involvement in self-help groups: to what extent should statutory agencies try to establish such groups or become involved in existing ones? There is no easy answer here; some self-help groups welcome professional involvement, while others are very chary of their intervention. If there is no local group, it may well be possible to help get one underway, bowing out gracefully as soon as it has gained some momentum. There has been growing interest in providing support to self-help in the past few years. A new government programme has set up local development officers for this purpose and an independent national centre, The National Self Help Support Centre, has been established in London.[9] Both should prove a source of advice for local professionals concerned about their role. In addition, on the basis of earlier work in this area, Ann Richardson has produced a guide expressly for this purpose.[10]

We have avoided recommending the introduction of widespread counselling for parents on the grounds that this is easy to propose and extremely difficult, as well as expensive, to effect. It is an issue, however, which deserves serious exploration. It is evident, and not surprising, that many parents find it enormously painful to contemplate the move from home. In the long-term interest of the mentally handicapped sons and daughters, there may well be a case for professional intervention in helping parents to 'let go'. Indeed, some parents actively seek such help, recognising that they are unable to take the necessary initiatives on their own. Interestingly, Hugh Card argues that parents should be helped to view 'the pain and sense of loss entailed . . . as the important parental sacrifice rather than the continued care for the mentally handicapped person in the parental home.'[11] As with other help, intervention in this respect may prove more fruitful if undertaken before parents are very elderly.

All of these suggestions have concerned helping parents to begin the process of making a break from their sons and daughters. But it is equally important that help is provided to those undergoing a move and, not to be forgotten, the period after it. In fact, the parents interviewed who had seen their children leave home were generally very content with the help they received. Both their social worker and the hostel staff had seemed sympathetic to their needs for support and given generously of their time in order to help. Several parents spoke of being touched by inquiries, made after the move, into their own welfare, as well as into that of their son or daughter.

There is also a need to work with the mentally handicapped people themselves. Our reasearch has focussed on parents and we have purposely avoided placing too much weight on their interpretation of the views of their sons and daughters. To discover *their* attitudes and feelings about a move from home would be a different study. But it is not difficult to argue the case for greater attention to helping them to articulate what they want. There is considerable interest in various ways of doing this, from self-advocacy schemes to providing key workers to speak for them. The effect on both their lives and those of their parents might be quite striking, as they might themselves begin to work through the normal adolescent processes of making the break.

Attention must also be drawn to the needs of mentally handicapped people for emotional support once they have left the parental home (and, indeed, for those leaving hospitals). One of the basic needs a home provides is a sense of security and the feeling of being cared for. When most people leave home, they do so either to get married or to live directly or indirectly with others who provide them with a great deal of this support. For people with a mental handicap, the overwhelming majority of whom will never marry, it can prove much more difficult to secure such friendships; yet it is equally important for their welfare. We would urge greater attention, both once they are on their own *and* before they leave home, to this key element in the well-being of mentally handicapped people.

There is one additional group affected by the continued residence of people with mental handicaps in the parental home, whose needs need to be addressed. These are the siblings who agree to take on the responsibility for their handicapped brother or sister when their parents die. Our study, of course, was not directed to their particular problems, but it would appear that there are substantial numbers either currently looking after a sibling or expected to do so some time in the future. Many are undoubtedly happy to be in this situation and coping well, but we suspect there are others who find themselves with little sense of choice and little vocation for the work. Again, we would urge some attention to be given to their needs, as well as to the handicapped brothers and sisters being cared for by them.

The two policy issues raised by this study are highly interrelated. One could be seen as a matter of 'structure': the need to make appropriate residential provision for people with mental handicaps when they move from the parental home. The other is more a matter of 'process': the need to provide help to parents in making the break. But it is evident that local efforts on behalf of these twin objectives must be conjoined. There is little point in providing excellent residential care if parents are unwilling or unable to let their son or daughter go. Similarly, there is little point in providing help to parents in this respect if there is no suitable provision to which their son or daughter might reasonably move.

Concluding comments

Our research was at no stage intended to produce recommendations either for individual families or for government policy on when people with a mental handicap should leave home. This is, quintessentially, a private matter. Nonetheless, it is clear that there is a real problem here, deriving from the simple fact that in most families something eventually has to be done. If moves at the point of crisis – parental death or incapacity – are to be avoided, it is necessary to help families to undertake a move some time before.

There are three issues which need to be underlined here. First, on a very general level, it is clear that there are, as in every family, potential conflicts between the interests of parents and those of their sons and daughters. Parents themselves are often painfully aware of these differences and deeply torn between what is best for themselves and best for their child. As we have shown, some parents wish for time to themselves, but feel their son or daughter needs to be at home. Other parents, in contrast, strongly want the presence of their son or daughter in the household, but feel that it would be to his or her long-term benefit to settle elsewhere. The distress in making decisions in the light of this ambivalence is very striking.

Second, there are very different issues arising in the case of young and older families. It is not simply that parents' (and their son's or daughter's) perspectives may differ, depending on their own age. It is also that the experience of any move has very different implications for them. For the young person with a mental handicap, it may seem a very natural progression to a new life; for the older one, it may well be viewed as a move away from what had been seen as a permanent home. For the parents, too, the move is likely to mean very different things. For younger parents, it may – either immediately or eventually – be seen as the source of a new freedom, the opportunity to do what they want, like other people of similar age. For older parents, in contrast, it may be seen as 'the beginning of the end', with increasingly little to devote themselves to for the remainder of their lives.

Third, and an even more general point, the heterogeneity of the families under question must be heavily stressed. Parents caring for handicapped sons and daughters at home should be seen to share neither the same circumstances nor the same attitudes to the move from home. Their perspectives differ substantially, arising largely from the relative stresses or joys of their own situation. Some are young and strong and have a great deal of social support. Others, however, are getting on in years, in poor health and considerably isolated. A few have clear plans for the move and little need for help in this matter. Most, however, seem to view the long-term future as a matter of deep uncertainty and worry. Any consideration of appropriate policies to these populations must take the complexity of these varying circumstances into account.

The conclusions and policy recommendations of our study are not largely new. What our research has done is to elucidate and illustrate parents' feelings about seeing their handicapped son or daughter leave their home. As a means of adding force to our conclusions, however, it may be useful to show the extent to which others share a common fire.

First, the need for local professionals to play a full part in helping families to plan for the future of their handicapped sons and daughters, has been well stated by The Independent Development Council for People with Mental Handicap. Having urged 'as a matter of the highest priority' that every family have a social worker, it proposes:

> One of the ongoing tasks of the social worker will be to discuss with families a range of issues surrounding the question of the needs of their son or daughter for somewhere to live . . . There is in our view *no excuse for a local social service office being faced by an emergency on the death of a parent*, and being forced to 'find a bed' for a mentally handicapped person they have never met.[12]

The difficulties sustained by parents in this process, and the policy inplications stemming from them, have been well put by Alison Wertheimer:

> The experiences that many of these families have had in the past, of either being ignored by the services, or being given help in a fragmented and *ad hoc* fashion, will not make them easily receptive to help when it is offered. Too many of them have struggled on their own for thirty years or more and will almost certainly be wary of whatever help may be offered. The 'hit and run' approach must be replaced by an approach which is consistent and longer term.[13]

Furthermore, the difficult problem of balancing the potentially conflicting needs of mentally handicapped people and their parents has been raised by the recent report of the National Association of Health Authorities on older mentally handicapped people:

> A very delicate balance needs to be struck between the need to encourage mentally handicapped adolescents to grow up and to become independent – which will help them to cope when their parents can no longer look after them – and the understandable protectiveness of parents for young people who are generally vulnerable. Equally, in some circumstances, the determination of parents themselves to be independent and not to seek help may not be in the long-term interests of their child.[14]

Second, the need for more – and more suitable – provision for handicapped adults has become the subject of mounting concern. To cite two examples, the report of the Jay committee argued:

> The major challenge in the field of mental handicap is, we believe, to establish a system of residential services for *adults* which goes beyond the family home, hospital ward or local authority home options and provides a high quality of service in *each* area.[15]

The need for further information on this issue is stressed by the recent House of Commons Social Services Committee report on community care:

> We recommend that local authorities seek urgently an estimate of the number and severity of disability of mentally disabled adults living with elderly parents and inform the Department of the service consequences.[16]

Finally, the broad need for more attention to those mentally handicapped people currently living at home has been argued from virtually every corner. To give just the most recent – and potentially most influential – example, the report on community care argued:

> It is vital that the pressing problems confronting those mentally disabled people already living in the community be more fully taken into account in developing policies of community care. We recommend that future DHSS and local community care documents should have greater regard to those mentally disabled people living outside institutional care.[17]

References and notes

1 Jane Ritchie and Jill Keegan. Housing for mentally ill and mentally handicapped people. [Carried out on behalf of the Department of the Environment] London, HMSO, 1983.

2 Mary McCormack. Away from home: the mentally handicapped in residential care. London, Constable, 1979: p 10.

3 See 2: p 9.

4 A useful book for social workers, which explores a number of relevant issues, is David Anderson. Social work and mental handicap. London, Macmillan, 1982.

5 Wolverhampton Social Services Department. Adult mentally handicapped people living at home: their future care; a guide for parents and relatives. Wolverhampton SSD, 1982.

6 See 2.

7 Edward Whelan and Barbara Speake. Learning to cope. London, Souvenir Press, 1979.

8 Gerald Sanctuary. After I'm gone: what will happen to my handicapped child? London, Souvenir Press, 1984.

9 For further information about the government programme, contact Peter Cartwright, Self-Help Alliance, Volunteer Centre, 29 Lower King's Road, Berkhamstead, Herts HP4 2AB (telephone 04427 73311) and for the National Centre, contact Mai Wann, National Self Help Support Centre, National Council for Voluntary Organisations, 26 Bedford Square, London WC1B 3HU (telephone 01-636 4066)

10 Ann Richardson. Working with self-help groups: a guide for local professionals. London, Bedford Square Press, 1984.

11 Hugh Card. What will happen when we've gone? Community Care, 28 July 1983, pp 20–21.

12 Independent Development Council for People with Mental Handicap. Memorandum submitted to the House of Commons Social Services Community. In: Community Care, Volume III, Appendices to the minutes of evidence: p 707 (italics in original).

13 Alison Wertheimer. Living for the present: older parents with a mentally handicapped person living at home. London, Campaign for People with Mental Handicaps, 1981: p 34.

14 National Association of Health Authorities in England and Wales. Growing older: mentally handicapped people and their families: a plan for action (mimeographed). Birmingham, NAHA, 1985.

15 Parliament. Report of the Committee of Enquiry into Mental Handicap Nursing and Care (Chairman, Peggy Jay) Cmnd 7468. London, HMSO, 1979: p 47 (italics in original).

16 House of Commons. Community care with special reference to adult mentally ill and mentally handicapped people. Second report from the Social Services Committee, session 1984–85. Volume I. Report (Chairman, Mrs Renée Short) London, HMSO, 1985: p lxxxix.

17 See 16: p xvi.

Appendix A: USEFUL ORGANISATIONS

Advocacy Alliance
115 Golden Lane
London EC1Y 0TJ
01-253 2056

Campaign for People with Mental Handicaps
12A Maddox Street
London W1R 9PL
01-492 0727

Contact a Family
16 Strutton Ground
London SW1P 2HP
01-222 2695

Down's Children's Association
3rd floor, Horne's Premises
4 Oxford Street
London W1N 9FL
01-580 0511/2

Independent Development Council for People with Mental Handicap
King's Fund Centre
126 Albert Street
London NW1 7NF
01-267 6111

MENCAP
(Royal Society for Mentally Handicapped Children and Adults)
117–123 Golden Lane
London EC1Y 0RT
01-253 9433

MIND
(National Association for Mental Health)
22 Harley Street
London W1N 2ED
01-637 0741

National Autistic Society
276 Willesden Lane
London NW2 5RB
01-451 3844

National Federation of Gateway Clubs
117 Golden Lane
London EC1Y 0RT
01-253 9477

Spastics Society
12 Park Crescent
London W1N 4EQ
01-636 5020

Appendix B: RESEARCH DESIGN AND METHODS

Note: This is an abridged version of a technical report prepared on this study. Copies of the full report are available from Jane Ritchie, SCPR, 35 Northampton Square, London EC1V 0AX.

The research design

The research was carried out in two local authority areas and had four separate but linked parts:

A postal survey of all parents known to be caring for a mentally handicapped son or daughter at home, to provide a profile of the characteristics, circumstances and experiences of families in the two study areas.

Depth interviews with parents to explore their feelings about caring for their handicapped son or daughter at home, their consideration of alternative arrangements and their thoughts about, or plans for, the future.

Group discussions with parents to examine their attitudes and reactions to alternative forms of care.

Interviews with parents of handicapped sons or daughters who had recently moved from home (carried out in a separate area).

The study areas

We decided at the outset to confine the study to two local authority areas, as a considerable amount of preparatory work would be required both to become familiar with the available provision and to gain access to a sample of parents. We decided to choose areas which varied in character in order to maximise coverage of different populations. The two areas involved a metropolitan and non-metropolitan authority, one in the north and one in the south. Both were unexceptional in terms of their provision for people with mental handicap. A brief description of the areas, and their provision for people with mental handicap, is given in the introduction to this paper.

The two authorities have not been named since the specific locations in which the research was conducted is seen to be immaterial. The problems addressed are common to all areas and any comments about a known authority would prove a distraction from the central issues.

The postal survey

It was our aim at this stage to try to contact all parents known to be caring for a mentally handicapped son or daughter at home. As there was no centralised register of such parents in either area, it was necessary to approach all agencies who were likely to know of parents. These agencies included the ATCs and other day centres, the social services departments, the district health authorities, hospitals, the local Mencap societies and other voluntary organisations. A total of 38 different departments, organisations or groups were involved. Because the names and addresses of parents could not be released to the research team for reasons of confidentiality, we asked all the above agencies to forward the postal questionnaire on our behalf. This meant that there was inevitably some duplication in the families known to the different agencies, which we tried to overcome.

The postal questionnaires were sent out in May 1984. The response rates were 62 per cent in the southern area and 68 per cent in the northern area. It is likely that these are slight underestimates of the proportion of eligible people covered, given the problem of duplication.

No names and addresses of parents were released to the research team during the administration of the postal survey. In order to obtain this information, a separate form was sent with the postal questionnaire, asking parents to give their name and address if they were willing to take part in the later stages of the research. Of those who replied to the postal survey, 59 per cent returned this form (the rate was identical in the two areas).

The depth interviews

The parents approached for an individual interview were selected from among those who returned the address form. The sample was purposively selected to cover a range of different characteristics and circumstances. Those taken into account were the age and marital situation of the parent, the age and severity of handicap of their son or daughter, the use of formal day care arrangements, the extent of experience of other care arrangements (either short or long-term), and the level of thought about, or planning for, the future. Selection was not on a proportionate basis; in other words, the interview sample did not mirror the characteristics and circumstances of those taking part in the postal study. This would have resulted in too low a representation of certain groups, such as parents above retirement age. Altogether, 51 families were approached for interview, and 49 full interviews were obtained.

The interviews were carried out from a subject guide and were unstructured in form. This method was determined by the complexity and sensitivity of the decision processes being questioned, combined with the fact that it was a relatively new area of investigation and all the relevant subject areas could not have been predetermined. We felt that a responsive, flexible and exploratory mode of interviewing was required. We have no doubt that this was a correct decision; it would have been quite impossible to capture the subtleties and complexities of parents' views with a predetermined and structured form of interview.

The interviews were carried out in the summer and autumn of 1984 by specialist research interviewers from SCPR. In the case of two parent families, an attempt was made to see both parents, either on their own or together. In some cases, the son or daughter with mental handicap was also present during the interview and involved in some parts of the discussion. This material has not been used, since the questioning focussed on the parents, and there was no opportunity for a fair representation of the views of the son or daughter.

All the individual interviews were tape recorded and subsequently transcribed verbatim. The subsequent analysis entailed three stages: constructing an index of the key themes and issues; establishing charts from the material within a thematic framework; and analysis of the charted material, both within and between cases.

The group discussions

The principal purpose of the group discussions was to consult parents about the forms of residential provision they thought should be available. In particular, we wanted parents to describe the kind of home they envisaged for their own son or daughter if he or she were no longer able to live with them. A group forum was chosen so that the advantages and disadvantages of different forms or features of care could be debated and any consensus of opinion gauged.

Six group discussions were held, three in the northern area and three in the southern. The parents were selected in exactly the same way as for the individual interviews, so that again a range of circumstances and experiences could be represented. The groups ranged in size from seven to ten people, involving 51 parents in total. The response to taking part and the level of attendance on the day was notably high.

The groups were conducted by two members of the research team. They lasted longer than had originally been planned, reflecting the considerable interest parents held in the subject. All the discussions were tape recorded and later transcribed verbatim.

The discussion had two parts. In the first, parents described their feelings about a possible move from home, highlighting many of the same issues covered in the individual interviews. In the second, the discussion focussed on the possible alternatives to home, both existing or as conceived by the parents. Some prepared information was given to parents as a basis for debate.

Interviews after a move

We decided at the outset of the study to interview some parents whose son or daughter had recently moved from home. Originally, our plan was to try to talk to parents both before and after a move so that both the anticipation and the reality could be described, preferably within the two study areas. This plan had to be abandoned, primarily because there was very little movement from parental care to other arrangements in either area, except in difficult or crisis circumstances.

We therefore sought out a location where residential provision had recently been opened for mentally handicapped adults coming from the parental home. On finding one, we were unfortunately unable to secure the cooperation of the relevant local authority. The local Mencap society helped us to locate parents whose son or daughter had recently undergone a move. Although we approached roughly 20 parents for interviews, only six agreed to take part. We suspect that the experience may have proved too painful (and too recently so) for many parents to be willing to be involved.

The interviews with these families took place in early 1985 and were similar in form to those with parents whose son or daughter was still at home. Again, they were tape recorded and transcribed verbatim. Analysis was also undertaken in a similar way. We are well aware that the interviews were too small in number to have undue weight placed on them, but would note that their accounts provided evidence which was entirely consistent with findings from other parts of the study.

A note on the measure of severity of handicap The measure of severity of mental handicap used in this study was derived from information provided by parents in the postal survey. The parents were asked about their son or daughter's abilities to undertake the following activities:

feed him/herself;
take a bath or all over wash;
use the toilet (for both bladder and bowels);
make a hot drink or snack;
do the washing up;
find his/her way around the immediate neighbourhood, including crossing roads;
use public transport;
use money to buy things.

For these questions, answers were pre-coded as follows:

on his/her own	(we gave a 'score' of 1)
only with some help	(we gave a 'score' of 2)
not at all	(we gave a 'score' of 3)

Parents were also asked if their son or daughter was able to :

stay in the house for an hour or more;
read a few words in simple sentences;
talk in a way that could be understood by strangers.

For these questions, answers were pre-coded yes or no:

yes	(we gave a 'score' of 1)
no	(we gave a 'score' of 2)

The possible 'scores' ranged from 12 (for the most able) to 33 (for the least able). To determine categories of the level of handicap, individuals were assigned as follows:

15 or less: very mildly handicapped
16–20: mildly handicapped

21–25:	severely handicapped
26–33	very severely handicapped

It can be seen that these categories are not related to any other systems for classifying severity of handicap, although the component items were drawn from a number of other classification schemes. We appreciate that our categories may be seen to be fairly arbitrary. They did enable us, however, to identify variations in the broad severity of handicap for purposes of the subsequent interviews and analysis.

FURTHER READING

The following is not a complete bibliography, but is intended to serve as a guide for those who would like to read further on this subject.

After I'm gone: what will happen to my handicapped child? Gerald Sanctuary. London, Souvenir Press, 1984.

Away from home: the mentally handicapped in residential care. Mary McCormack. London, Constable, 1979.

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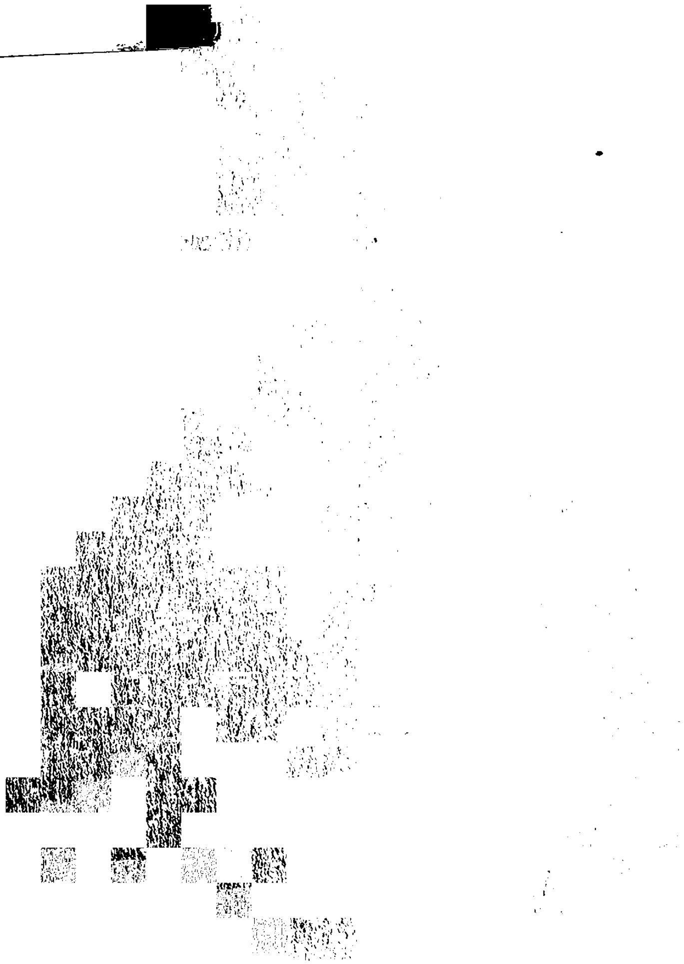
They keep going away: a critical study of short-term residential care for children who are mentally handicapped. Maureen Oswin. London, King Edward's Hospital Fund for London, 1984.

What will happen when we're gone. Hugh Card. Community Care, 28 July 1983.



What will happen to our handicapped son or daughter after we've gone? Should a move from home take place long before that time? These questions deeply worry parents whose son or daughter has a mental handicap. When they have been looking after a son or daughter over many years, 'making the break' becomes one of the hardest decisions they ever need to make. It raises fundamental questions about the nature of their family and their need for one another. It also raises questions about where their son or daughter might go.

This book explores parents' views on these key issues and examines their implications for policy. It is based on research carried out over two years. The analysis is intended for health and social services professionals involved in providing support to families or responsible for managing and planning arrangements for residential care.

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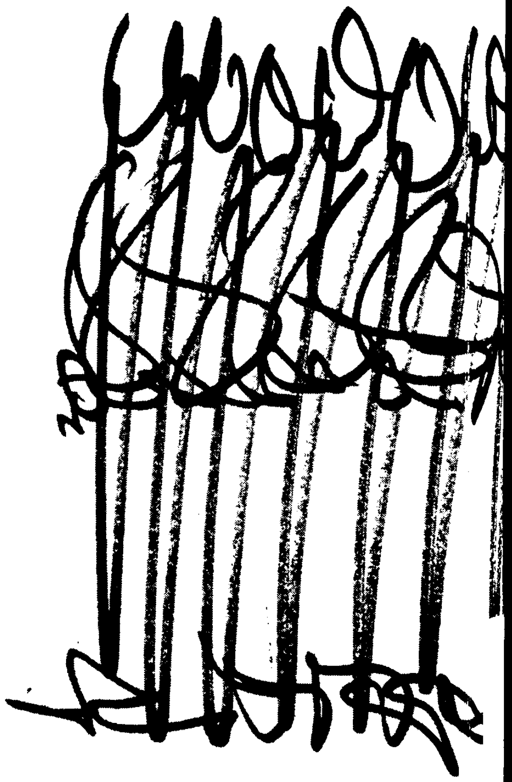

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