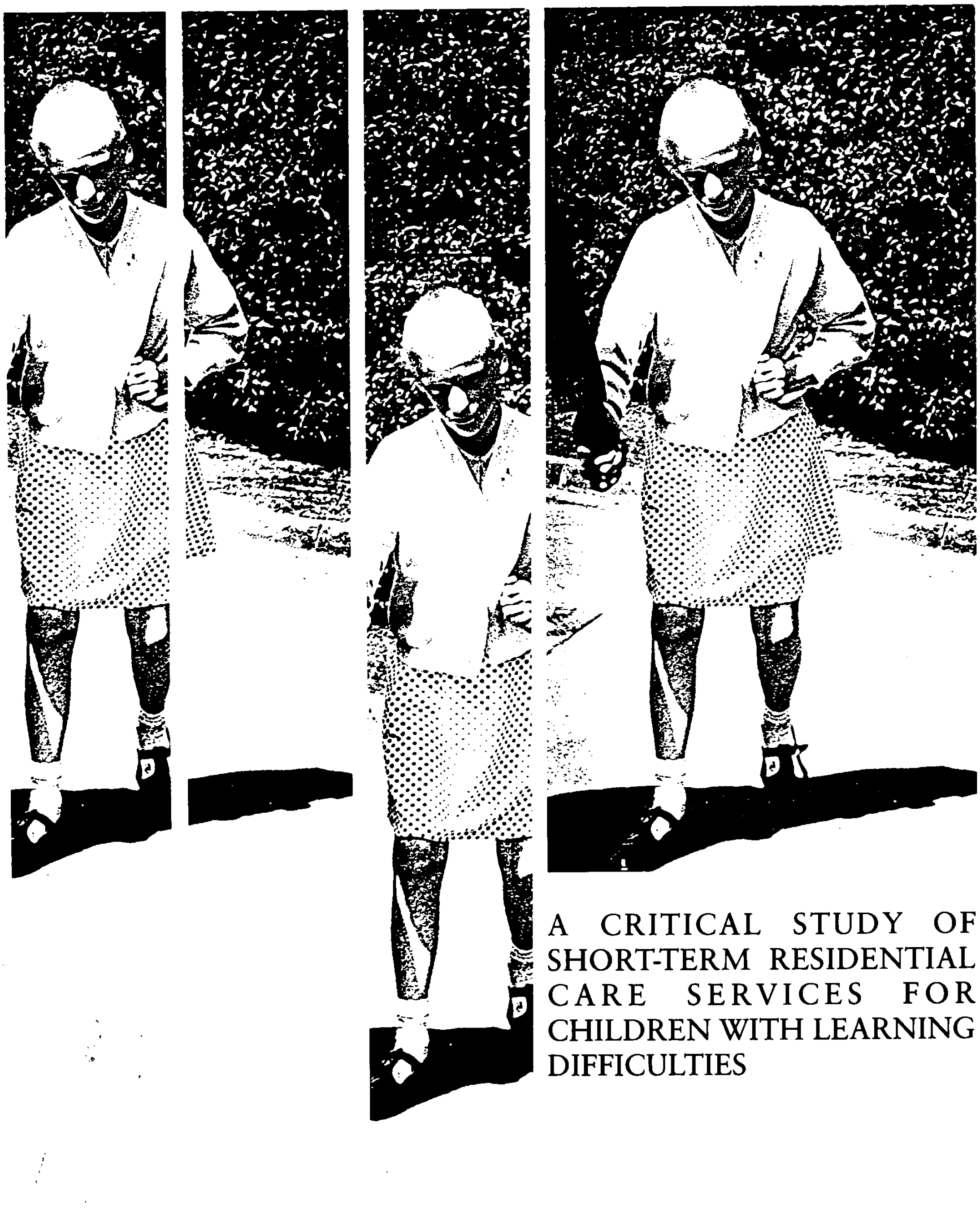
THEY KEEP GOING AWAY



A CRITICAL STUDY OF SHORT-TERM RESIDENTIAL CARE SERVICES FOR CHILDREN WITH LEARNING DIFFICULTIES

KING EDWARD'S HOSPITAL FUND FOR LONDON

MAUREEN OSWIN

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Note about new edition

When this book was first published in 1984, the term 'children with mental handicaps' was in use. In the late 1980s, however, that term was discontinued as being derogatory and labelling and the words 'children with learning difficulties' was substituted; and this term is now in use in current books, reports, in verbal discussion and policy documents. The words 'mental handicap' remain, however, in this book as it would have been a complicated and costly business to make so many alterations in the text. The author wishes to apologise if this causes offence to anyone.

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King Edward's Hospital Fund for London

'...so he went from lap to lap, never getting lasting comfort'.

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Introduction to new edition

When I was doing the research for this book in the late 1970s and early 1980s, I was concerned and upset to see so many children with handicaps continuously going in and out of unsuitable forms of residential care for short periods so that their parents could have a rest from caring for them.

I saw very homesick children, and young staff who lacked training in child care, and tired parents who did not like the way their children were looked after but felt helpless to do anything about it. I also met managers and directors of services who were so far removed from the services they managed and directed that they had no idea that what they described as a good family support service was probably doing more harm than good. However, in addition to seeing bad care I also saw staff who were willing to be self-critical, who wanted to know more about child care and were attempting to organise services in a better way for the children. And I met professionals and families involved in family-based respite care, the innovative form of family support which had been pioneered in Leeds and Somerset and was still in its early stages of development.

Although there were some good examples of services, such as the family-based respite care schemes and a few particularly well-run residential care units, it would not be an exaggeration to say that short-term care through the 1970s and at the start of the 1980s was mostly a hotch-potch of ill-defined plans being badly carried out; in most instances it was a sincere attempt to provide periods of respite for parents, but it was usually done in a way that made the children feel very insecure and unhappy. In this book there are many descriptions of sad and neglected children in residential short-term care premises; and one of my most worrying findings was that some children were getting repeated, and increasingly longer, periods of short-term care and were gradually drifting into long-term care without their parents or the professionals seeming to be aware of it.

Before the book was first published I gave a series of talks about my findings to meetings of parents and professionals, and suggested that the majority of short-term care services were merely a crude 'separation service' and, in some instances, resembled little more than the 'kennelling of children'. At one meeting there was a shocked silence in the hall when I said this and the director of social services who was chairing the meeting was visibly annoyed; however, some parents and professionals stood up and agreed with my criticisms and said that the service ought to be organised in a more child-oriented way. But has anything radically changed for children having short-term care since this book was first published in 1984?

There have certainly been developments in political philosophies about services for people with learning difficulties, physical handicaps, psychiatric illnesses and the frailties of old age. For example, the white paper *Care in the community* emphasises the principle of services being provided in people's own homes rather than in hospitals and institutions; and many of the big, old institutions are in the process of closing down. The developments which are likely to have most influence on future short-term care services for handicapped children are:

the findings of current research;

the increase in family-based respite care schemes;

the 1989 Children Act.

The following discussion looks at some aspects of these three developments.

Current research

Does recent research show that the care of children having short-term care is noticeably better organised and of better quality now than it was when I was doing the research which resulted in this book? Sadly, the research done by Carol Robinson and Kirsten Stalker of the Norah Fry Research Centre in the late 1980s suggests a continuation of some of the shortcomings which concerned me in the late 1970s and early 1980s and which are described in detail in this book: for example, children using hospitals for short-term care; poor record-keeping; children at risk of drifting into long-term care after repeated periods of short-term care; the staff of residential units unhappy about having to provide for a mix of long-stay and short-stay children on the same premises; the children's home routines not being maintained while they were away from home; parents worried about their children's safety in the premises they were staying in; the mixing of boisterous children with frail children; and children suffering homesickness.

In my book there is only one chapter given to family-based respite care, which at the time I called 'special fostering'. As I had, for a number of years, observed very unhappy scenes among groups of children in institutional settings where there was a lack of mothering and no continuity of care (because of inappropriate training and the constant changes of staff) I felt that children who received family-based respite care would probably suffer less homesickness than those I met in institutions. However, Robinson and Stalker suggest that there is also homesickness among children having short-term care in other families and it may not be recognised by parents and carers as related to separation worries.

Indeed, Stalker found evidence of the same sort of secrecy in the organisation of family-based respite care as I found in the organisation of short-term care in residential units and hospitals – for example, children not being honestly told that they were going away and their cases being smuggled out of the house.

One of Robinson and Stalker's recommendations is that local authorities should appoint a coordinator of short-term care services, and they emphasise the need for parents to have a choice of alternatives of respite care. They also refer to helpful schemes, such as the recruitment of 'companions' for handicapped children to take them out in school holidays and the employment of a helper to go on holidays with families in order to give specific help with the handicapped child.

The research of Robinson and Stalker could have far-reaching positive effects on the organisation of future respite care services if their findings are acted upon by planners in local and central government. But do planners and policy-makers take sufficient notice of research? For me, at a personal level, the particular findings of Robinson and Stalker of the late 1980s which mirror my own of the late 1970s put a depressing perspective on research and prompt the following questions. Who reads research – other researchers or the people who can change things? Why do the same problems keep recurring which are repeatedly shown up by research? Why do children continue to suffer unacknowledged neglect and homesickness? How many times do researchers have to say these things before services are planned more positively? And, at the end of the 1990s, will there be yet more research by more people showing the same defects in services that I found in the late 1970s and that Robinson and Stalker found in the late 1980s?

The increase in family-based respite care schemes

There has been a very positive development of the family-based respite care services throughout the 1980s. In 1975, the idea of children going to stay with another family to give their own parents a rest from their care was very unusual, and the two first schemes were only just being pioneered in Leeds and Somerset. But by the time this book was first published in 1984, there were more than 50 local authorities providing such support schemes. And there was already a nucleus of concerned professionals who were working in family-based respite care schemes meeting regularly at the King's Fund Centre, London, under the auspices of Joan Rush, to discuss aspects of the new service.

Other such groups outside London were also starting to meet as the schemes were rapidly increasing nationwide. From the meetings of all these groups came the idea to form an association and, consequently, the National Association of Family-based Respite Care was formed. The Association held its first general meeting in London in October 1989 and its first national conference in Nottingham in July 1990.

There are now 220 schemes in the United Kingdom.* With all these schemes now established and the National Association firmly launched, it is obvious that in less than 15 years the family-based respite care service has created a new way of thinking about support services for families who have a child with a physical handicap or a learning difficulty. And what is so encouraging is that the majority of the members of the Association are willing to be self-critical about the schemes and are very concerned for the children who use them. The conference in Nottingham, attended by over 300 people, discussed such issues as homesickness, support for parents, support of carers, siblings, the training of carers and the introduction of the children to their care families. The Association will probably have an extremely positive effect on the future organisation of family-based respite care services.

The 1989 Children Act

In addition to the research of the Norah Fry Research Centre and the formation of the National Association of Family-based Respite Care, the next most influential factor on the quality of future short-term care services for children with learning difficulties is likely to be the legislation brought about by the 1989 Children Act. In December 1988, the Lord Chancellor introduced the Children Bill into the House of Lords with the words: 'The Bill in my view represents the most comprehensive and far-reaching reform of child law which has come before Parliament in living memory.'

For the first time in children's legislation it has now been spelt out that children with handicaps have the same legal right to good care and good services as children without handicaps. What might the

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* Figure supplied by Christopher Orlik, Development Officer for the National Association of Family-based Respite Care (1990).

1989 Children Act do specifically for children with learning difficulties who will be getting short-term care in the future? Under the following seven headings I have picked out for emphasis those sections of the Act which seem to be particularly relevant to issues of family services and child care which I raised in this book.

One – Keeping parents informed

Local authorities will be required to not only keep themselves informed as to the extent to which there are children with handicaps in their area, by maintaining an area register of handicapped children (Schedule 2 paragraph 2 (1)) but shall 'publish information about services provided for them ... and take steps as are reasonably practical to ensure that those who might benefit from the services receive the information relevant to them'. (Schedule 2, paragraph 1(2)(a) (b).)

If this requirement is followed through successfully it should mean that children and their parents will be helped promptly, because they will know what services are available. This could prevent the occurrence of a crisis which might result in inappropriate services being used and a long-term separation.

Two – Providing a range of appropriate services

All local authorities will be required to provide services 'designed to minimise the effect on disabled children within their area of their disabilities; and to give such children the opportunity to lead lives which are as normal as possible'. (Schedule 2, paragraph 6(a) (b).) Interpreting this section of the Act to mean that services should not make matters worse but should lessen the effects of the children's disabilities makes it a very honest admittance of past short-comings in services for handicapped children.

If this requirement is followed through it should prevent children being given the inappropriate neglectful care which has been described in the chapters of this book. This section of the Act could cover the provision of such services as: physiotherapy to lessen the likelihood of deformities for children with cerebral palsy; the provision of appropriate aids within the home and within schools; holiday help for parents so that children can live at home in their school holidays; and residential care to be given in premises which are as normal as possible (that is, not in hospital wards or large institutions). This section could also be interpreted to mean that children should always be cared for by staff who have appropriate training in child care, play and child development and the special needs of children with handicaps.

Three – Helping children who are living with their own families

Local authorities will be required to provide appropriate support services for handicapped children living with their own families: for example, advice; occupational and recreational activities; home helps (which may also include laundry services); adequate transport so that other services can be taken advantage of; and assistance to enable the parents and their handicapped child to have a holiday. (Schedule 2, paragraph 8(a) (b) (c) (d) (e).)

This very comprehensive requirement covers services which are essential to parents caring for a handicapped child. It is to be hoped that local parent groups and professionals will use this section of the Act to ensure better services.

Four – Providing appropriate residential care

The Act requires that if local authorities are providing residential care for children they should ensure that the 'accommodation is near his home'. (Part III, Section 23, paragraph 7(a).)

If this requirement is followed through it should prevent children going into residential care premises which are long distances away from their family homes, and it should help to prevent parents hunting about for various more distant services.

Further, Section 23 states that the local authority should ensure that 'the accommodation is not unsuitable to his particular needs'. (Part III, Section 23, paragraph (8).) Regarding the use of voluntary organisation accommodation it requires that local authorities should satisfy themselves that whether the accommodation is inside their area or outside their area it should be '... satisfactorily safeguarding and promoting the welfare of the children ...' (Part VII, Section 62, paragraph (1) (a) (b).)

Perhaps these requirements will prevent children going into institutions (for example, mental handicap hospitals) which have long been recognised as inappropriate residential care placements for children. But it is to be hoped that the words 'not unsuitable to his particular needs' will not be used in a way that allows discrimination against, or excludes, those children who have very severe multiple handicaps or challenging behaviour. And it is to be hoped that these sections of the Act *will* actually be applied in respect of handicapped children having short-term residential care.

Five – Safeguards which may prevent short-term care drifting into long-term care

The Act requires that where a child is accommodated by any health authority or local education authority or is in residential care, nursing or mental nursing homes '...for a consecutive period of more than three months or with the intention, on the part of that authority, of accommodating him for such a period...' they should inform the local authority of the child's origin before he went into residential care or, if the child was not ordinarily resident in any particular authority, then the local authority of the area in which the residential accommodation is situated should be informed of the child's presence in that accommodation. The relevant local authority, once informed, should then 'take such steps as are reasonably practical to enable them to determine whether the child's welfare is adequately safeguarded and promoted' while he is in the accommodation. (Part XII, Sections 85 and 86.)

These sections should be the means of alerting local authorities to the possibilities of some children remaining in residential accommodation for a longer period than can be defined as receiving short-term care. However, having the regulation time as three months does not adequately spell out the need to look closely at how children can become long-term residents in premises of whatever responsible authority simply due to having a succession of short stays which *drift into long-term care* in such a subtle way that it can be overlooked in the process of it happening.

The children referred to in this book as at risk of drifting into long-term care certainly did not have a period of care amounting to as long as three months to start with, but had a pattern of care such as one week a month, or a month in and a month out of hospital, or every other week or every weekend; the process of drifting into long-term care was not at all obvious and could take one to three years of this type of in-and-out and gradually lengthening regime for the child. The Act's cut-and dried three month period, although giving an alert to local authorities, does nothing to get to grips with (a) those children who are drifting into long-term care because of frequent and increasing periods of short-term care, or (b) the problems of the children at risk because they keep going away from home to give their parents a break and have such frequent short periods of residential care that they may just as well not have a family at all.

Six – Inspectors of residential accommodation

The Act allows for the Secretary of State to have very broad supervisory powers which will permit premises which accommodate children 'to be inspected from time to time...' The named categories of premises relevant to the children referred to in this book include children's homes run by local authorities or local education authorities or voluntary organisations, health authority residential care premises and independent schools and private residential homes. (Part XI, Section 80, paragraph (1).)

The inspectors will be empowered to 'inspect the children there and make such examination into the state and management of the home or premises and the treatment of the children there as he thinks fit.' (Part XI, Section 80, paragraph (6).)

This allowing of inspectors responsible to the Secretary of State to enter premises and look at the welfare of the children is going to be immensely important for children in residential care. One immediately thinks that the quality of care for children in residential accommodation will now be safeguarded. However, will the inspectors understand the needs of children with learning difficulties and additional problems such as challenging behaviour or severe physical disabilities or physical frailties? Will the inspectors be expert enough to see through a sometimes showy and superficially pleasant environment to the neglect of children with severe handicaps? For example, children can be left lying about on cushions surrounded by expensive toys and mobiles but never touched or spoken to (as I have referred to in the chapters of this book).

Will the inspectors understand enough of what can be done to help children with challenging behaviour to allow them to be critical of premises in which groups of children just mill about, without emotional security or individual care, loosely supervised by disinterested staff in an environment completely lacking any family-style amenities? And what about the multiply-handicapped children who spend long periods in paediatric wards and other health care premises being 'assessed', or having an assessment and short-term care combined, or are constantly in and out of paediatric wards because they have chronic health problems? Will the care of these specially vulnerable children be changed in any way because of the new Inspectorate of the 1989 Children Act?

Unless the inspectors themselves have the experience of working with severely multiply-handicapped immobile children and/or children with challenging behaviour there is a danger that they will function in no more effective manner than most official visitors usually function – that is, those from health authorities, local authorities and community health councils who tend to be easily misled by staff and managers into thinking that everything possible has been done for the children.

Seven – Consulting the children

The Act says that the child's wishes should be considered regarding the accommodation he is given and, before he is given accommodation, the local authority should '... so far as is reasonably practical and consistent with the children's welfare – (a) ascertain the child's wishes regarding the provision of accommodation; and (b) give due consideration (having regard to his age and understanding) to such wishes of the child as they have been able to ascertain.' (Part III, Section 20, paragraph (6).)

The question must here be raised as to how much will this section of the Act be applied to handicapped children using short-term care accommodation, especially those children with severe multiple handicaps or challenging behaviour? How will a child who dislikes going away from home and is homesick every time he has short-term care be able to benefit from this section of the Act? Who will be in his own home to hear him say 'I don't want to go'? Will his homesickness be recognised as going 'against his wishes'? Will the needs of his parents to have a break take precedence over his needs as a homesick child? And how will children who cannot speak at all make their wishes known?

With a service as complicated as short-term care there is always going to be a dichotomy between the needs of the parents and the needs of the child, and there is always the inclination to see the parents' needs as most important because they will ultimately affect the care of the handicapped child and any other children in the family. The philosophy of short-term care is based quite clearly on the principle that if the parents get over-tired and exhausted they cannot adequately care for their children and their health may be at risk, so poor quality short-term care or short-term care that makes a child homesick is thought to be better than no short-term care at all.

It is to be hoped that this section of the Act will be used by parents, social workers, teachers, community nurses and other appropriate professionals, including officers in charge of residential care, who all need to collaborate in discussion about the children's wishes and reactions and likely homesickness, with particular attention being paid to children who cannot speak. If this does not happen, then the legal requirement that the children's wishes should be consulted will be made a nonsense in the case of children with communication problems.

Perhaps the developments referred to in this introduction to the new edition may ensure that the last decade of the twentieth century will finally get services right for handicapped children; but to make the Act work, bearing in mind that it is a legal tool that is ineffective unless people know how to use it, there has to be a body of people (local professionals, politicians, parents) who understand the Act and who know about current research and can ensure that both the Act and research are used wisely. But that body of people has to understand the needs and development of handicapped children. If the people who can influence services do not understand the needs of the children as individuals then most short-term care services will continue to be a hotch-potch of good and bad services – the crude separation service which I refer to in the chapters of this book. The opening words of the 1989 Children Act, describing the needs of the children as being of 'paramount consideration', will be our main hope for the 1990s and the opening of the new century.

Maureen Oswin
1990

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During the course of the study I met many parents and care staff and other professionals and they very willingly gave time to talk to me about local services and their own experiences, and I have to record my gratitude for all their kindness and help which frequently extended to additional hospitality such as lunches and suppers and drying of rain-soaked papers and clothes, and lifts over unfamiliar cities, new towns and bleak moors.

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Finally I have to thank Joyce and James Robertson for their permission to quote on page iv from the script of their film 'John'. I hope that in some small way this report will speak for the countless children who, like John, sadly have to 'go from lap to lap' because of the way in which residential care is organised.

Maureen Oswin
1984

Foreword

When the history of residential care for mentally handicapped children comes to be written it will be seen that Maureen Oswin's accurate and compassionate observations of individual children living permanently in long-stay hospitals were the flash point which changed official thinking on this issue. 'The long-stay hospital is no place for a child to grow up in' said Patrick Jenkin, then Secretary of State for Health and Social Services at a MENCAP conference in 1980.

Maureen Oswin's new study of short-term residential care for mentally handicapped children will shake many of us from a tendency to complacency. The theme of her research is that child care principles are too often ignored in the present organisation of short-term care. 'At no time should any decision be taken about a handicapped child that would not be considered right for an ordinary child.' The problems of lack of continuity of care, changing staff and wards, are often seen at their worst in the long-stay hospitals whose organisation is such that it is difficult to maintain good standards of child care. But hostel-type care, whether run by NHS or local authority, does not escape criticism. Lack of contact with parents, units which are too large and lack of staff supervision and support, are frequently found. 'A dangerous autonomy' can lead to falling standards.

But it is in the heartbreaking accounts of individual children's homesickness and distress that Maureen Oswin's observations make their keenest point. Her descriptions of a school bus taking a child to a hostel passing the end of the road where he lives and his distress at this, and the confusion caused by units not following parents' routines for bedtime and meals, point out how mentally handicapped children can be made to suffer unnecessarily. She also highlights the failure of many professionals and parents to recognise the symptoms of separation in mentally handicapped children, symptoms which have long been recognised in non-handicapped children returning home after separation from their parents. She observes that the professionals employed to organise the separation of the children from their parents seem to be surprisingly ill-informed and insensitive to the stress that might be caused by the experience and urges recognition of and help with the stress felt by parents, staff and children. A recognition of grief in the child, which she describes as a 'recurrent bereavement', must be an integral part of staff training.

This research urges the virtues of 'special fostering'. Her studies of individual special foster parents speak of 'the joy of a full professional life as well as a happy home life' experienced by the foster parents. And the parents of mentally handicapped children speak warmly of the support and friendship experienced in the short-term fostering setting. But it is the children themselves who benefit most from such special fostering arrangements, as Maureen Oswin so clearly describes.

As with her books about children living permanently in long-stay hospitals, this book should prove to be another milestone in public and professional thinking about mentally handicapped children and their families.

Peggy Jay
1984

Introduction

> All this long hot weekend I have been conscious of Jake in the background. He came to the ward on Friday and his father collected him this afternoon (Sunday). Most of the time he just stood by the television set, whether it was on or off, clutching a carrier bag which he'd brought from home. Nobody took any notice of him. The staff only made contact with him when it was necessary to take him to the bathroom for washing and changing or to the table for a meal. Nobody took any interest in the contents of his carrier bag or encouraged him to empty it and play with the things he had brought from home. When his father arrived today he saw him standing by the television set holding his carrier bag and he said to the staff 'I see he's all ready for me. How's he been?', and to Jake he said 'Did you show the nurses your toys?'. The staff replied 'He's been fine, no trouble at all. Hope you and your wife enjoyed the break from him and managed to get out somewhere nice'. When Jake and his father had gone the staff remarked to each other how glad they were to help the parents by taking him for short-term care every other week-end. They did not speak of the drear homesickness and boredom that Jake probably experienced during his weekends away from home.

The above description of Jake came from notes I kept during a study of long-stay children in mental handicap hospitals during 1975–77. It was one of several references made to children who came into the wards to receive short-term care so that their parents could 'enjoy a break'. Engrossed in my study of long-stay children, I could give little attention to those who came for short-term care, but was aware that many of them were very homesick and I wondered how so much abject misery could go unnoticed by caring staff and families. It seemed almost as if parents and staff were colluding with each other to deny the children's misery because there was general agreement that short-term care was a good idea and a valuable form of family support. Long-stay hospitals which were offering this support were considered to be in the forefront of progressive ideas.

Jake was just one of an increasing number of children having regular weekends in a mental handicap hospital. But if his parents had witnessed his loneliness during the time he spent away from home, would they have used the facility again? Or would they have just tried not to think about it, knowing that there was no other form of help for them? Would they have complained and asked for more activities and individual care for him? Would complaining have done any good or would their complaints have merely offended the staff who sincerely believed that they were offering a good service by looking after Jake every other weekend?

Twentieth century knowledge and literature about childhood separation, based on research findings and reports of government committees and on personal experiences recorded in biographies and novels, make it plain that if children have to suffer a separation from their family home, it is desirable for the experience to be managed very carefully so as to avoid distress (Robertson[1], Platt report[2], Freud[3], Hall and Stacey[4], La Fane[5], Battye[6]). Insensitive handling of childhood separation is understood to cause severe stress and likely emotional ill-health in later months or years of the person's life (Bowlby[7]).

Noting the sad experiences of Jake and other short-term care children, I wondered who was ultimately responsible for admitting them to hospital wards which were short-staffed and rarely able to provide adequate care for the long-stay children, let alone take on the care of homesick short-stay ones as well. I wondered how it was that their separation experiences were not being managed in a kinder manner, in keeping with present-day knowledge about the need to handle childhood separation with care and sensitivity. How was it that the principles of care in separation now considered important for ordinary children were not being applied so rigorously for mentally handicapped children, and in some instances not being applied at all? Why did professionals offer short-term care so casually and without any apparent thought for the children's feelings? 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*, and from this emphasis had grown a belief that they did not require the same standards of care and consideration as ordinary children going away from their families. Was this because handicapped children were thought unlikely to suffer from normal homesickness, or was their homesickness denied because the need to give their families a break was thought of paramount importance?

It was not only disquieting to realise that children receiving short-term care were given the experience in a manner which would be stringently avoided for non-handicapped children, it was also disquieting to note that these periods of separation were considered a very desirable and progressive form of family support. Accepting that the development of short-term care had grown from a sincere wish to provide family support services, but suspecting that it was sometimes overriding the feelings of the children, I began this study in 1977 and planned to look broadly at the following aspects of the service:

1 How families were using short-term care and what they wanted from such a service.

2 The care that the children were receiving.

3 The aims of staff providing short-term care.

The purpose of the study was to try and obtain some insight into short-term care and see whether it would be helpful to draw up guidelines for what appeared to be a rapidly developing and widely diverse form of family support. Visits to a variety of facilities showed a muddle of provision and practices, some being astonishingly crude. But within the muddle there was also a wealth of ideas, some good services and a sense of commitment amongst the professionals. There was also evidence that parents were beginning to influence and improve the services for their children. It was difficult to organise the study in a way that would give a reliable national picture about the developments taking place. Indeed, there *was* no national picture. The infinite variety of services illustrated the autonomy, for good or bad, of local government.

Between 1977 and 1981 long visits lasting between six and twelve weeks were concentrated on four main areas and approximately 100 short visits were made to other places. Contact was made with 150 families using some form of short-term care. They were in three groups.

Group A consisted of 81 families who were informally interviewed on at least one occasion either in their own homes or in the units their children were using. The interviews lasted between one and six hours. The fullest information was obtained through the contact made with this group of parents because their children were met, visits were made to the local special schools, and periods of between six and twelve weeks were spent in the units they were using. Thirty-one of these 81 parents were using an ex-paediatric ward which had been converted into a Family Help Centre (Collingwood)*, 24 were using a new local authority hostel built specially for short-term care purposes (Rivermead)*, 17 were using a new mental handicap hospital (Field Lodge)* and nine were using a short-term fostering scheme in Middleshire*. All four facilities had been started at approximately the same time and had been functioning for between one and two years when the study visits began.

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* These names are fictitious in order to protect the privacy of the parents and staff who helped by giving information for this study.

Group B consisted of 42 families who answered questions by post about their use of short-term care. The information was very helpful but some of it was incomplete, and it was not possible to meet all these parents and their children or to visit all the units they were using.

Group C consisted of approximately 25–30 families who had discussion about short-term care either in their own homes or the units they were using or at parent meetings. The meetings with these parents were fairly casual and generally occurred because they had heard about the study from other parents and wanted to share in giving information. However, the meetings were very helpful in spite of being unstructured.

Most of the discussion in the following pages is based on the information obtained through contact with the 123 families in Groups A and B, but information given by those in Group C has been included where relevant.

The purpose of the visits and interviews was to obtain parents' views on the services they were using, to find out if possible how the children felt about the services (through observation and being with them when they were away from home), and to gather information from the staff about the organisation and aims of their services.

The parents were questioned about how they found out about the short-term care services; their first reaction to being offered such help; their anxieties or satisfaction with it; their children's reactions to the experience; sibling opinion on the absence of the handicapped children; whether they would recommend the service to other parents; and how they thought the service might be improved. It was plain that the parents were glad of an opportunity to talk to somebody about services. They were not only interested in the development of their own local services but also keen to know what was happening in other areas.

In addition to interviewing parents, information was also gathered on approximately 600 children receiving some form of short-term care: their handicaps, ages, schools attended, their family situation and their pattern of using short-term care. These children were living in the districts used in the study. Due to the poor quality of record-keeping, both in local authority social services facilities and in health authority services, it was not always possible to obtain a full picture of each child's situation. It was found that some children had been receiving short-term care in hostels or hospitals regularly for four or five years, but the care staff, social workers and planners had very little information about their abilities and family situation or, if they had, this information had not been shared in the interests of the children. So although care staff might have been receiving children in and out for a number of years, they were ignorant of certain aspects which might have helped them to form a full picture of the children they were caring for, such as what the children did at school, the sort of house they lived in, whether they had grandparents or siblings, the names of the siblings, the names of pets, whether they had a garden or a car.

Although some of the information obtained on the 600 children was incomplete, and in some cases of doubtful veracity, the attempt to gather it was thought worthwhile as an exercise which might throw light on how short-term care was being used and by whom, and whether there was any pattern of use that could be detected in a period of two to three years which might be significantly related to the children's ages, handicaps, and family background. (See Appendix for a consideration of this information as it applied to one particular locality and facility, bearing in mind that it gives a broad picture rather than a reliable analysis of the situation.)

It is hoped that this report will encourage parents and professionals to look critically at what is good and bad about short-term care and have discussion together about how future developments not only meet the needs of parents but also consider the needs of the children.

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1 The development of short-term residential care services

What is short-term care?

In the context of this study the term short-term residential care refers to the arrangements whereby a handicapped child is looked after in a place other than his own home for a period of time which includes at least one night but does not exceed three months; the arrangement is made with the agreement of the child's parents or, if he is 'in care', his foster parents and the local authority social services department which is responsible for him. Various terms are used to describe short-term residential care: phased care, programmed care, relief care, respite care, holiday care, social admission, planned care and shared care.

The purpose of the arrangement is that families will have a break from the care of their handicapped child. During the child's absence the parents may take the opportunity to go on holiday, visit places or undertake activities which would have been difficult with the handicapped child, give the siblings some extra attention, or complete a household task such as decorating. Parents who are caring for a child with disturbed sleep patterns may use the short-term break in order to catch up on their own sleep. As well as giving the families a rest, short-term care is sometimes recommended so that the professionals can give the children a medical or psychological assessment or specialist help with a behaviour problem, or sleeping, eating and toilet habits, or in learning a skill such as dressing or feeding themselves.

The receipt of short-term care does not mean that a child who is not already in the care of his local authority has to be received into care. Arranged on the recommendations of a nurse, doctor or social worker who believes that the child should be placed in a hospital or some other residential premises in order to relieve his parents, this temporary stay away from his family comes under the provisions of the Health Service and Public Health Act (1968) Section 12 (Section 21 and Schedule 8 of the National Health Services Act 1977).

Where is it provided?

Short-term care is being provided in a number of different places:

in hostels which may be run by the local authority social services departments or the local health authority;

in local education authority special school hostels which have a joint arrangement with the local authority social services department to provide 'social care' as needed, in addition to their usual function of providing Monday to Friday boarding accommodation for pupils travelling long distances;

in hospitals (paediatric, mental handicap, general);

in voluntary organisation Homes, some of which may receive financial aid from the local authority in which they are sited or from other local authorities which send children to them for care;

in Homes belonging to local groups of parents, some of which may be aided by joint funding from the local authority and the health authority;

in foster families, some of whom may have been recruited specially to provide short-term care to handicapped children; others may be regular foster parents. To distinguish the short-term fostering of handicapped children from the regular fostering of children who might be described as 'in need', some local authorities call the special foster parents such names as 'link families', 'substitute families' or 'befriending families'.

The growth of short-term care

The provision of short-term residential care as a means of helping families with handicapped children is not a new idea. It received official recognition from the DHSS in January 1952 with the publication of Circular 5/52. Prior to 1952 all mentally handicapped persons who were admitted to mental handicap hospitals were supposed to be certified and detained under one of the sections of the 1913 Mental Deficiency Act and it was not permissable to admit a person on an informal basis although, in fact, some mental handicap hospitals were already admitting children for short-term care to give family relief. Such admissions were referred to by the Medical Officer of Health for London in his Report of 1952:

> 'Although not specifically authorised to do so, the Fountain Hospital had, during 1951, admitted children for short periods to provide a measure of relief to hard pressed parents. The position with regard to this short-term care was regularised by the issue of Ministry of Health Circular 5/52 on January 21st 1952.'*

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* Report of the Medical Officer of Health for London County Council (1952).

The Circular, entitled *Short-Term Care of Mental Defectives in Cases of Urgency*, recommended that:

> '. . . in many families where there is a mental defective, critical situations may arise in which it is urgently necessary that the defective should be cared for elsewhere than at home for the time being. Examples of this are the illness of a member of the family; the mother being in urgent need of a holiday . . . The powers conferred on Local Health Authorities under Section 28 of the National Health Services Act, 1946, are considered adequate to authorise them to find accommodation and pay for all or part of the maintenance of the defective. The period of care should not, of course, exceed the period of special need and one, or at most two months, would be the normal maximum.'[1]

Under the recommendations of Circular 5/52 there was a growth of 'uncertified cases' admitted to the mental handicap hospitals of England and Wales; 2000 such admissions were recorded in 1955 and a further 500 were boarded out or placed in Homes.[2] The satisfactory working of this method of caring for mentally handicapped persons, on an informal basis according to family needs, influenced the 'informal admission' procedure which was eventually permitted by the passing of the Mental Health Act 1959.

Mental handicap hospitals and local authority or voluntary society Homes were not the only places providing short-term care in the 1950s and 1960s. Some paediatric units or children's wards in general hospitals were also offering such help. In a paper in the Lancet in 1962, Dr Simon Yudkin described a scheme in which 'for the past four years mentally defective children have been admitted to the children's wards of Whittington Hospital during the summer months to enable their families to have a holiday. The pressure on children's beds (for sick children) is less during the summer, and other hospitals might consider a similar scheme'.[3] More than 60 children in three years were cared for in the children's wards of Whittington General Hospital by this scheme. The *deliberate planning* of a special short-term care scheme for mentally handicapped children was unusual enough in the late 1950s to prompt Dr Simon Yudkin to write his Lancet paper about it, but such care was also taking place on an *unplanned* basis in the wards of other hospitals.

Paediatric wards or units were used for the most severely multiply handicapped children. Those who were ambulant and active tended to go either to mental handicap hospitals for short-term care, or their parents made arrangements with private and voluntary Homes in a fairly limited manner according to what they could afford, perhaps just booking their children in for a fortnight each summer. Dr Yudkin wrote that his scheme was 'most suitable for severely subnormal and bedridden children'. His language in describing multiply handicapped immobile children has dated, but the belief that paediatric wards are suitable places for the short-term care of very dependent children has persisted.

The exact number of handicapped children who are annually being admitted for short-term care to paediatric wards and general hospitals in England and Wales is not known because the records of these 'social admissions' are not kept separately from those of sick children. The words of the senior social worker of one large hospital for children described a common situation in 1981: '... this hospital does admit children for short-term care but no statistics are kept as they are entered as routine admissions. They are children who are very seriously mentally and physically handicapped and are admitted to give parents a break ...'*

Paediatric hospitals used for children's short-term care may be a long distance from the families they serve, some being the country branches of city hospitals. The social worker attached to the country branch of one large city hospital recorded: '...in 1980 we had 946 patients, 150 of whom at a rough guess, may have been short-stay ... it would be reasonable to say that we cater for approximately 250 short-term patients a year who have a complete range of handicaps...'*

Mentally handicapped children are also being admitted for short-term care to local 'cottage' hospitals which have empty beds because seriously ill people are now going for treatment to the large centralised district general hospitals. Some small hospitals which were faced with closure after the development of big district hospitals are being regularly used for the short-term care of handicapped and/or elderly people as well as for the treatment of mildly or chronically sick people. As with the paediatric hospitals, the national figures of short-term care admissions to 'cottage' hospitals are not known.

Although short-term care admissions to 'cottage' hospitals, general hospitals and children's wards may be advised by social workers and doctors who sincerely believe that the families' interests are best met in this manner, the practice is to be deplored because:

a a sick children's hospital or a ward in a 'cottage' or general hospital is an inappropriate place in which to provide residential care for children who are not ill: a hospital can never meet their need for a normal homely environment;

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* In correspondence with M Oswin (1981).

b some of the hospitals used for short-term care are a long distance from the families' neighbourhood so the parents are not familiar with the hospitals and find difficulty in getting to them;

c if paediatric and general and 'cottage' hospitals continue to provide short-term care there is a danger that the true size of local family needs will be hidden from the local authority departments which should be planning neighbourhood based short-term care facilities for all the families who require such support.

It would seem very important for the DHSS to obtain full information on admissions of children to hospitals for short-term care by asking hospital staff to keep the short-term care statistics separately from those of sick children's admissions. The DHSS should also issue firm advice against continuing the practice of using hospital wards for short-term care as it is not in the interests of any child, no matter how handicapped, to have recurrent periods in hospital in order to give the parents a break.

The undesirability of admitting children to general hospitals for short-term care was referred to in discussion with a nursing officer of a paediatric department in a general hospital when she described the difficulties of caring for the mentally handicapped children and sick children together. She was against the practice because she felt her staff could not meet the needs of the mentally handicapped children. She thought that the local authority should have been providing them with appropriate accommodation.*

During a summer holiday period, as many as 26 mentally handicapped children went through the sick children's wards of one general hospital and nearly half of them were lively and ambulant. The sick children's nurses said that they did not have the right resources for short-term care children who needed to be out of doors and busy with play activities. The nurses were also very worried about the sick children who were in the ward, some of whom were very ill and recovering from operations and in no state to have lively and sometimes irresponsible mentally handicapped children around them.*

In one visit to a general hospital during the research it was noticed that two mentally handicapped children, who were receiving short-term care in the sick children's ward, were dressed in their nightclothes and sitting listlessly in the corridor outside the sister's office where they could be 'kept an eye on'. They were obviously a source of worry and irritation to the nurses who were busy looking after seriously ill children.**

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* In a meeting with M Oswin (1978).

** Noted in one of the visits made by M Oswin 1978–79.

During the 1960s and 1970s the majority of local authorities were providing very little short-term care of their own, but they would sometimes pay part of, or all, the cost of a child's accommodation in a voluntary organisation home if the parents were recognised as needing a break. The White Paper, *Better Services for the Mentally Handicapped* referred to the scant provision (long-stay or short-stay) made by local authorities for the residential care of mentally handicapped children:

> '. . . in 1959 local authorities were again put under a duty to provide residential accommodation for the mentally handicapped . . . at the end of 1969, 24 of the 157 authorities in England and Wales still had no arrangements of this sort at all, either for children or adults. Another 64 in England and 5 in Wales had no such arrangements for children'.[4]

The limited provision made by local authorities for the residential care of mentally handicapped children was also referred to in the 1974 report of the study group appointed by the Secretary of State for Social Services to look at mentally handicapped children in residential care. They estimated that out of the 8500 mentally handicapped children receiving long-term residential care in England and Wales there were as many as 6500 in hospitals and only 1000 in local authority homes, the remaining 1000 being in voluntary homes (600), in private homes and schools (300) and in foster homes (100).[5]

The 1980 DHSS publication on progress and problems in mental handicap services recorded little progress being made in the first half of the 1970s: between 1969 and 1977 the places in local authority residential homes for mentally handicapped children (long-stay or short-stay) increased by only 400, from 1200 in 1969 to 1600 in 1977. The publication stated: 'Provision is very variable with 40 out of 109 local authorities still providing no places of their own'.[6]

The above references to Cmnd 4683, the Harvie Report and the DHSS document on priorities are important for an understanding of the development, or *non*-development, of family support services, for they illustrate that the NHS was continuing in the tradition of being the main provider of residential care for mentally handicapped children and that local authorities were not recognising their responsibilities in this field. Mental handicap hospitals, unlike paediatric, general and 'cottage' hospitals, do keep statistics of their short-term care admissions, listing them as discharges within three months after an admission for a 'social reason'. The figures in Tables 1 and 2 are significant, showing the increased use of mental handicap hospitals for short-term care.

Table 1 Discharges within three months of admission for social reasons to mental handicap hospitals and units in England

Year	All-aged persons	Aged 0–19
1970	5119	3588
1971	5673	3897
1972	5578	3720
1973	5723	3806
1974	6087	4193
1975	6699	4594
1976	7698	5037
1977	8352	5419
1978*	9010	5797
1979*	10261	6664

* Provisional figures

Source: Mental Health Enquiry Statistics and Tables. Reproduced with the permission of the Controller of Her Majesty's Stationery Office.

These figures do not refer to individual persons but to the actual separate discharges of persons; individual children are being readmitted to mental handicap hospitals any number of times a year for short-term care, some having as many as 15 or 20 admissions every year on a system of planned or 'phased' care. Table 2 gives some details of the ages of short-term care admissions of children and young people up to the age of 19.

The continuously steady figure of between 300–400 admissions for children aged under five during the years 1970–1979 is disquieting. It is not desirable for any small child to have recurrent periods away from home amongst strangers, and to spend that time in the unsuitable environment of a mental handicap hospital must be extremely unsettling. It would definitely seem more appropriate and kinder for these young children to be cared for in their own homes through a reliable baby-sitting service or by another family through a 'befriending' or 'foster' scheme.

The figures in Table 2 are generally worrying, not only because of the number of under-fives. There was a marked rise in the admissions of children aged 5–9 between 1970 and 1979, and for the age group 10–14 the admissions doubled, whilst for those aged 15–19 they trebled. The admissions for all ages (0–19) between 1970 and 1979 showed a steady increase, with *over 3000 more* short-term care admissions to mental handicap hospitals in 1979 than in 1970. It is a matter of considerable surprise that so many children continued to have short-term care in mental handicap hospitals throughout the 1970s in view of reports drawing attention to the deprivations of the

Table 2 Discharges, within three months of admission for social reasons, of children and young persons to mental handicap hospitals and units in England, by age on leaving

Year	Aged 0–4	Aged 5–9	Aged 10–14	Aged 15–19	Total
1970	420	1455	1032	681	3588
1971	497	1462	1273	665	3897
1972	417	1295	1280	728	3720
1973	366	1211	1338	891	3806
1974	427	1280	1420	1066	4193
1975	387	1279	1671	1257	4594
1976	363	1484	1810	1380	5037
1977	341	1572	1899	1607	5419
1978*	333	1607	2041	1816	5797
1979*	378	1708	2441	2137	6664

*Provisional figures

Source: Mental Health Enquiry Statistics and Tables. Reproduced with the permission of the Controller of Her Majesty's Stationery Office.

long-term children who were living in poor conditions in these hospitals, but perhaps parents and professionals thought that the effects of poor deprived conditions were not likely to be so serious if the children were only in for short-term care.

Throughout the 1970s the NHS continued to be the major provider of short-term residential care, giving it either in mental handicap hospitals or paediatric units, and it was invariably tacked on to the already over-strained long-stay services instead of being regarded as a specialised service in its own right. The NHS is not (and has never been) an appropriate body to take on the responsibilities of providing residential child care, because it has neither the most suitable premises nor the trained child care staff. But there seem to be two reasons why it has been the main provider: first, severely handicapped children are not always included in the local authority residential care services because they traditionally come under hospital services; second, parents with severely handicapped children tend to have more contact with professionals in the health services (paediatric and/or mental handicap) than those in social services, therefore NHS professionals are often the first to recognise when a family needs help and are the most willing to initiate a short-term care service.

One of the best family support services to be developed under the NHS in the 1970s was Honeylands, started by Professor F S W Brimblecombe in Exeter, Devon in 1967. This paediatric unit aimed to provide continuous support for families with handicapped children, from babyhood to puberty, through diagnosis, assessment, therapy, parent advice and counselling, day-care, short-term care and playgroups. Professor Brimblecombe believed that 'the availability of such a family support unit could diminish the strain on the families of handicapped children and help them to maintain normal family and social relationships'.[7] Referring to the concept of short-term care developed by Honeylands, Professor Brimblecombe wrote: 'The parents know that if they want to go out for an evening or away for a weekend, they can, without formality, arrange for the child to stay in the unit for the appropriate period . . . The amount of support given to particular children and their families varies. Some families make only occasional use of the residential facilities, while others are regular users . . . during the last seven years only two children under the age of 11 from the Exeter area have, as far as I am aware, been committed to permanent care in a mental subnormality hospital. For all the remainder the parents or foster parents have, with the support provided, continued to bring up their handicapped children as a member of their own family.'[7] A hundred and thirty-nine children in the Exeter district made use of Honeylands for day care and short-term residential care between August 1973 and July 1974.

Dr Simon Yudkin's paper of 1962 and Professor Brimblecombe's paper of 1974 illustrated a developing awareness of family needs and the various efforts to meet them which were then being made by individual professionals working in the health services. A comparison of the two papers shows that in twelve years there had been a gradual shift towards a concept of developing a *whole family support service.* The Honeylands philosophy, unlike the Whittington scheme, emphasised that short-term residential care could be just one component in a whole network of local family support services. By the late 1970s many parents and professionals were thinking of the Honeylands model as the ideal, providing a variety of locally based services geared to the needs of families. Whether the services should be predominantly under health service provision, as at Honeylands, or whether the local authorities should take more responsibility, especially for the residential side of the family support, was a question which many people found difficult to answer. There was, however, general agreement that the provision of family support from small local units was good in principle and that short-term residential care was a very important part of that support.

Most literature on mental handicap services in the 1970s referred approvingly to the development of short-term care services:

> 'The provision of small residential units within the community where children can board weekly or live throughout most of the year could encourage the maintenance of ties between the child and his family, when he can no longer be cared for entirely at home. These units could also offer temporary relief to families during a crisis

> period such as when another baby is born or if one of the other children is taken into hospital, or simply when the parents feel the need for a short rest. For parents of the mentally handicapped child, the provision of short-stay hospital care has become a highly valued service over recent years, but most parents prefer the child to be placed locally, and if possible not within a hospital, bearing as it must, all the connotations of treatment and distress. The mere knowledge that this temporary relief was readily available locally, and without all those disturbing aspects associated with a formal hospital admission, would be beneficial in itself'.[8]

> 'There can be no doubt that families who have a mentally handicapped child living with them face severe strain. Most will derive considerable benefit and be able to continue to care for their child at home for a longer period, if from time to time the child can be admitted to short-term care. This may be provided by local authorities, by the NHS or by private or voluntary organisations'.[9]

> 'Families who look after a mentally handicapped relative have the right to expect where necessary short periods of relief as part of the wider system of community support . . . It is a crucial component of the wider range of family support services which are themselves central to the success of community orientated policy'.[10]

In 1979 the growing concept of family support services was given further impetus by the publication of the Jay report.

> 'Our model envisages that parents who decide to care for their child at home will quickly find themselves supported by a range of appropriate help . . . Domiciliary care of the most wide ranging kind may substantially change even further the number of parents who choose or are able to keep their child at home . . . The services will include short-term relief of various kinds, providing the parents with a chance to go shopping or to the hairdressers, and longer term relief to allow the family to have a holiday . . . We see this type of regular short-term care – which may be for a very short period of time or for a matter of weeks – as a vital element in the support to families . . . It is anticipated that such care will considerably reduce the stress on both parents and siblings, which is engendered in caring for the severely handicapped child and will allow them to care more effectively and for longer'.[11]

Influences on the growth of short-term care

The growth of short-term care, from its modest casual beginnings to the concept of it being an important aspect of comprehensive family support services, was influenced by the following developments which were helping to improve *all* services for mentally handicapped persons in the 1960s and 1970s and creating a climate which favoured children living with their families instead of in long-stay institutions.

First, parents and professionals were becoming increasingly aware that it was not right to put children into mental handicap hospitals for long-term care. Research into mental handicap services from the mid-fifties onwards was drawing attention to the inadequacies of long-term hospital care and recommending a shift to community care (Tizard[12,14], King[13], Morris[15], Jones[16], Oswin[17,18]).

Sensational hospital 'scandals' alerted professionals, parents and the public to the serious problems that could occur in long-stay hospitals when there were inherent deficiencies caused by shortages of staff, large numbers of residents and remoteness from normal community life. The most notable scandals occurred in Ely Hospital[19], Farleigh Hospital[20], South Ockenden Hospital[21], and Normansfield Hospital[22]. A curious aspect of the hospital 'scandals' was the speed with which each one was apparently forgotten and the fresh outbreak of public surprise and horror which greeted the appearance of a new one. In addition to these well-publicised shock reports there were a number of smaller internal enquiries in hospitals up and down the country which rarely reached the ears of the public but which nevertheless caused grave disquiet amongst local professionals.

However, in spite of the poor conditions in mental handicap hospitals, there was a lack of enthusiasm for a total swing away from hospital care and even some resistance to the idea. This was due to the paucity of most local authority provision and because many parents and professionals had little experience or knowledge of community care. The crude expression 'the devil you know is better than the devil you don't know' was very pertinent to the question of NHS hospital care versus local authority community care in the 1960s and 1970s. Parents and professionals alike had little or no confidence in what was being enthusiastically but often rather vaguely hailed as 'community care'.

During the 1960s and early 1970s the mental handicap services were also being influenced by the work of the Hospital Advisory Service (now the Health Advisory Service) which had been set up in 1969 following the Ely Hospital scandal by Richard Crossman, then Minister of Health, as a form of inspectorate for all long-stay hospitals (mental illness, mental handicap and geriatric). The mental handicap team of the Hospital Advisory Service was disbanded in 1972, and then followed a period when mental handicap hospitals received no inspection. This was changed in 1975 when Barbara Castle, then Secretary of State for Social Services, set up the National Development

Teams whose brief was to look at local mental handicap services, including hospitals and local authority provision, at the invitation of local bodies. The published reports of the Hospital Advisory Service from March 1970 until October 1972 and the National Development Teams from 1976 onwards, drew attention to an unchanging story of poor care in long-stay hospitals, largely caused by inadequate staffing and old-fashioned regimes.

It was surprising that the research and the scandal reports which so clearly showed the deficiencies of long-stay hospital care, took so long to influence changes: nearly 30 years separated the early research of Jack Tizard into the effects of poor hospital care on children's development and the first statement by government that children should not live in long-stay hospitals: '. . . large hospitals do not provide a favourable environment for a mentally handicapped child to grow up in', said Patrick Jenkin, Secretary of State for Social Services, in a speech at a meeting organised by the National Society for Mentally Handicapped Children in London in December 1980. In those thirty years the government and public had been beset by numerous reports, research, and public and private complaints about long-stay hospitals. Eventually parents became increasingly reluctant to put their children into long-term hospital care and added their voices to the debates of those professionals who recognised that mentally handicapped children did not receive adequate care in long-stay hospitals and that the local authority services were woefully under-developed.

In the latter half of the 1970s professionals working in the hospital services began to change their admissions policies, trying to keep the long-term admission of younger children (especially the under-fives) to a minimum and encouraging more short-term admissions at all ages. The use of mental handicap hospitals for short-term care was encouraged by professionals who, although they might have said that hospitals were inappropriate as permanent homes, at the same time believed that they could never be abolished altogether and could develop new roles as 'centres of excellence' providing family support and advice. Many parents agreed with this new concept of mental handicap hospitals and, whilst they might have adamantly refused to put their children into a mental handicap hospital for long-term care, they accepted short-term care admissions with few qualms and much appreciation.

But whilst some mental handicap hospitals were developing a new role in providing family support, others were 'running down', refusing long-term admissions and providing a minimum of short-term care in times of acute emergency only. One hospital, serving a catchment area population of threequarters of a million, restricted long-term admissions and had only two emergency short-term beds for children between 1975 and 1978. The local authority did not offer any local short-term care either. Parents living in areas where this sort of thing was happening could feel under a lot of stress during the long summer holidays when their children were at home all day. Some local authorities without any facilities of their own responded to the parents' needs by 'farming out' the children to holiday homes run by private or voluntary bodies, but these homes were usually a long way away. Some area health authorities responded by providing (at the discretion of the local paediatricians) a limited number of paediatric beds in their general hospitals for the short-term care of the most profoundly handicapped children whose families seemed to need a break. As referred to on page 11, the children's ward of one general hospital gave short-term care to 26 mentally handicapped children in one August school-holiday period. But not all of the children were immobile, and they caused consternation to the nurses tending sick children in the same wards who felt that they had neither the resources nor the time to give adequate attention to healthy handicapped children who required activities. It was this sort of situation that prompted local professionals to look at how they might provide parent support facilities, and encouraged the joint funding of community based short-term care schemes or the opening of short-term care wards in mental handicap hospitals which might otherwise have continued a policy of running down their services.

Second, parents were pressing for more services. The Royal Society for Mentally Handicapped Children and Adults, first founded in 1946 as the Association for Parents of Backward Children, is the largest voluntary organisation representing parents of mentally handicapped children. Its activities include publishing papers and booklets, providing courses for staff, exerting pressure on government to improve services, monitoring local facilities and educating the public about the nature of mental handicap and the needs of families. But parents' views have not been expressed solely through this national organisation: independent groups of local parents have pressurised local authority committees, insisting that the professionals responsible for planning local services should listen to their requests for an increase in community care. Parents in Islington, North London, who were reluctant to have their children living in the mental handicap hospital more than 20 miles away waged a persistent campaign in the mid-1970s until they succeeded in getting a jointly financed residential unit set up locally. And in 1975, in Bridgwater, Somerset, an amicable meeting between parents and professionals who were mutually enthusiastic about developing community care resulted in the setting up of the Somerset short-term placement family scheme.[23]

In addition to local campaigns there was an increase in organised meetings between parents and professionals deliberately seeking to share views and knowledge. A series of such meetings in London resulted in the publication of discussion documents about policies and practices in service provision.[24,25]

Third, the campaigns of pressure groups (not necessarily having a majority of parents amongst their members) influenced changes in mental handicap services in the 1970s, notably the Campaign for Mentally Handicapped People, MIND and EXODUS. Publishing well-informed pamphlets, they concentrated on campaigning for an increase in community care and the rights of mentally handicapped people to be listened to, to be educated and employed, to live in ordinary housing and have appropriately trained staff.

Fourth, public attitudes towards mentally handicapped people became more positive throughout the 1970s and helped to ease the way to developing more community care. Television programmes, radio and newspaper articles and the publicity given to the hospital scandals and research into hospital conditions began to arouse the public conscience to the injustices of poor services. The campaigns of pressure groups and the work of parents in describing their lives with handicapped children increased public awareness about the rights of mentally handicapped people. By emphasising the achievements and ordinariness of handicapped people the idea of community care has become more acceptable and this has helped professionals when setting up local schemes, although there are still some strong prejudices to break down.

Fifth, legislation and benefits. The Education (Handicapped Children) Act 1970 was a major step forward in the history of services for handicapped children because it brought severely handicapped children under the administration of their local education authorities and recognised their right to education. But the Act also had a social value – it meant that many families would be *daily* relieved of their children's care for the first time in their lives. Before it was passed, the chances of severely handicapped children going out of their homes away from their families for a short time every day depended on the availability of a place in a junior training centre* run by local social services departments or voluntary organisations, and some children did not get places because of the severity of their multiple handicaps or because of behaviour problems. If this happened they stayed at home all day and

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* These centres, earlier called occupational centres, had been run by local health and welfare committees until the Seebohm Report (1968) recommended placing them under the social services departments. The Education Act of 1970 finally placed them under the administration of the local education authority and recognised them as special schools and their staff as teachers.

confined their mothers to the house unless there were neighbours or relatives who could help.

It would be impossible to assess accurately all the social benefits of the 1970 Education Act, but it was probably a major factor in the reduction of numbers of young school-age children being admitted to long-stay hospitals for permanent care. The numbers of children aged under 16 living permanently in long-stay hospitals dropped from 7100 in 1969 to 2839 in 1979. This drop was definitely not due to large numbers of children being discharged. It was partly due to many having grown up and so then included in the hospitals' adult statistics, and partly due to fewer admissions because most parents felt the benefit of their handicapped children going daily to school and they were not seeking long-term care for them as much as the parents of the 1950s and 1960s did.

However, although parents felt the benefit of their children going to school each day, many felt that they also needed additional help during evenings and weekends and in the school holidays. Some were adequately supported by local adventure playgrounds, clubs for handicapped children and summer holiday play schemes run by students. But others wanted more regular relief than these schemes could give, and thought the extra help they needed could be in the form of short-term residential care. Most parents and professionals mulling over the idea of short-term residential care in the early and middle 1970s envisaged it being provided in hospitals or hostels, preferably being locally based and homely. The idea of regular short-term 'fostering' in another family was not much thought about or, if so, was not considered feasible or acceptable. The fostering schemes pioneered almost simultaneously in Leeds (Yorkshire) and Bridgwater (Somerset) in 1976 were unusually innovative and legislatively permissible under Section 12 of the Health Services Act, 1968 (Section 21 and Schedule 8 of the National Health Services Act 1977). This allows the children to be cared for by another family without going through child care legislation under the Children's Acts, so the parents do not lose their rights to their children.

The Education Act was the major legislation affecting mentally handicapped children and their families in the 70s but other legislation and national schemes were also influencing the development of parent support. The Chronically Sick and Disabled Persons Act 1970 enabled some families to receive aid from their local authorities to make adaptations to their homes (for example, building a downstairs bathroom, installing a stair lift, putting a ramp at the front door), so that they could more easily manage a very severely multiply handicapped child at home.

The Health Service Reorganisation Act 1974 reorganised the administration of the National Health Service and set up Community Health Councils in every health district. These statutory consumer pressure groups were given an official brief to examine the quality of health services provided for local people and to comment on plans. Each CHC included one or more members with a special interest in services for handicapped people. Some CHCs were disappointingly weak due to their members' lack of knowledge, but others influenced improvements in local health services for handicapped children by exerting pressure on area health authorities and providing public debate on issues affecting local handicapped people and their families.

The Health Service Reorganisation Act also enabled more liaison between local health authorities and local authority social service departments when planning services, and permitted the joint funding of community projects for mentally handicapped people. By 1980 it could not be said that there was full coordination of services provided by the two bodies. Clients were still falling through the net due to inefficient communications and defensive bickering between personnel, but in general there was an encouraging increase in cooperation and planning. Some districts appointed a health visitor or social worker to be responsible for families with handicapped children, a domiciliary occupational therapist or physiotherapist with a special interest in multiply handicapped children, or a psychologist who would specialise in helping parents with behaviour disordered children.

In some districts, professionals of the social services, health services and education worked closely together as an advisory team in accordance with the recommendations of the Court report[26] (1976) on the setting up of district handicap teams. And, as part of the changing image of mental handicap hospitals, small groups of mental handicap nurses began working in the community advising parents about the care of their handicapped children. Some areas had only one community mental handicap nurse working in a concentrated urban catchment area serving a population of half a million, others had a network of them working across a large rural area (Devon) or a team of community nurses based at the local mental handicap hospital (Princess Marina Hospital, Northampton). Sometimes the physiotherapists, speech therapists and psychologists working in mental handicap hospitals would go out and work in the community with families and in schools; and there was a growth of parent workshops run by professionals who were based in mental handicap hospitals.

An increase in social security benefits, for example, the Attendance Allowance and Mobility Allowance, made it financially a little easier to care for a handicapped child at home, as did the Rowntree Family Help Fund which was set up in 1973 to give financial aid to buy items such as spin dryers, washing machines, extra clothing, or special toys that could help the handicapped child overcome a particular aspect of his disability, or to pay for a family holiday, or a mother's driving lessons so that she could be more independent in caring for her child.

The legislation and benefits referred to in this section had many spin-offs, ranging from encouraging professionals' interest in supporting families to the easing of a parent's physical weariness in doing the daily washing. All these developments were making it possible to keep severely handicapped children at home.

Short-term care has to be seen as developing in conjunction with all the services and changes referred to above. The reactions of two parents sum up the improvements of the last thirty years:

> 'We had nothing when Louise was a child, no schools. She did not get into the junior training centre because she was too handicapped they said. There was no short-term care, it was not heard of then I don't think. We struggled on with her at home all day until she was ten and then had to put her into a mental handicap hospital. There was nothing else we could do.' (Seventy-three year old father speaking of the dilemma that he and his wife faced in 1954 when looking after their daughter who was severely mentally handicapped and cerebral palsied; she is now 37 years old and has been in hospital for 27 years.)

> 'With Nick at school all day and having one weekend a month away in short-term care I can manage; I would never consider putting him away into a long-stay hospital – what could *they* do for him that I cannot? I get the physiotherapist coming round or she sees him at school, and Rowntrees got me a washing machine last year.' (Thirty-six year old mother of an 11 year old, cerebral palsied boy totally dependent on her for all his care.)

Summary and conclusions

By the later 1970s a broad concept of care for mentally handicapped children and their families was emerging. Parents and professionals who had been pressing for better services were seeing the fruition of their efforts. Parents had more confidence to resist the traditional advice they had formerly been given to 'put your handicapped child away and forget about him'. They wanted recognition of their handicapped children's rights to a family life. The position of professionals who had long resisted change, because they had no faith in community care, was considerably weaker. There was a growing sense of agreement that mentally handicapped children should stay with their families and receive community support rather than be permanently accommodated in long-stay hospitals.

Residential short-term care as a form of family support was recognised as an important part of a 'whole packet of services' for families with mentally handicapped children at home. Begun almost casually thirty years ago by individual professionals wishing to offer occasional 'social help' to tired families, it had gradually increased until, by 1980, it was recognised as being as valuable as other, longer established, support systems such as the Home Help Service and Meals on Wheels for elderly and disabled people.

However, whilst there was general agreement that short-term care was a valuable form of support, the actual provision of it was disparate and uncoordinated, varying widely from area to area. There was no national overall plan, but a vast collection of different facilities which had been largely built up through the innovation and enthusiasm of local professionals and parents. In Exeter there was a family support system for handicapped children from babyhood to puberty based on the paediatric family support unit set up by Professor F Brimblecombe in Honeylands Hospital; Leeds and Somerset Social Services Department had pioneered fostering schemes to provide short-term care, and these were being copied in many other areas; professionals working in new small mental hospitals saw short-term care as part of a packet of services which would be provided for mentally handicapped persons from babyhood to old age under the auspices of a mental handicap hospital; some local authorities had decided to build hostels especially for short-term care children; sometimes local teachers were partnering parents in setting up short-term schemes, or local voluntary organisations had started schemes. But in many areas there was nothing available at all and parents were still using distant mental handicap hospitals or making do with sending their children to holiday homes for two weeks each year.

So, although everybody now agrees that short-term care is a necessary service, there is no national policy about what form it should take or who should provide it. Local autonomy, traditional to the organisation of health and social service provision in the United Kingdom, is encouraging innovation; however, the existence of local autonomy in itself does not necessarily create good services. It may encourage innovation in one area but in another it will merely mean a freedom to do nothing and to continue with outdated practices. So the absurd situation can arise whereby families living three or four miles apart may be receiving totally different forms of family support because they come under different boroughs which each have different mental handicap policies.

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2 Making use of short-term residential care

'It's our life-line. He goes in every other weekend.' (Parents of an active nine year old boy.)

'We'd never want our child to go away, not even for one night.' (Father of a 14 year old, cerebral palsied girl.)

'I don't use it more than twice a year – a week in March and a week in October, that's all, that just suits me.' (Widowed mother of a seven year old boy with Down's syndrome.)

Who uses short-term care and why

It would be a mistake to assume that parents who use short-term care for their mentally handicapped children probably have problems such as poverty, single parenthood, poor housing or large families, or that they are older parents who are finding the care of dependent handicapped adolescents an increasing burden. They come from all social backgrounds, their ages vary from under 20 to over 60 and their children have a wide variety of handicaps and abilities.

However, certain family situations will create more need for support; for example a 45 year old divorced mother caring for a totally dependent ten year old son and also looking after an elderly mother, may need to make extensive use of short-term care. And in those families where the father's work takes him away from home for periods – lorry drivers, servicemen, merchant seamen, politicians, executives representing their firms overseas – the mother is likely to need the support of short-term care because the absence of her husband places her temporarily in the position of a single parent. For instance, in a naval port a 20 year old mother with a four year old mentally handicapped son and a new baby to look after was having to make massive use of short-term care for the handicapped child during a period when her husband, a young naval rating, was sent on a course to another port. The mother's need and loneliness was increased by the fact that she was many miles from her own parents and relatives and could not call on them for help, a situation which is very common to young married couples in HM Services. Young parents living in new towns and those who have been rehoused in 'overspill developments' in areas a long way from their place of origin will be similarly in need of support because the move deprives them of the help once given by their extended families.

However, the use of short-term care by families with special needs should not detract from the fact that it is also used extensively by families who have apparently few problems and fairly able mentally handicapped children.

> Mr and Mrs Anderson had been using short-term care for two to three nights every month for more than eighteen months, for their son Bertie who was aged six. Bertie was fairly able, could walk and feed himself and could understand speech, but he was sometimes incontinent and also had poor sight. The Andersons also had another child, a daughter three years older than Bertie. The family lived in a large detached house. Mrs Anderson did not work. Mr Anderson was an accountant. To outward appearances they had few problems; they lived comfortably and Bertie was manageable and getting on well in school. But short-term care had made their lives easier as it had reduced the tension sometimes caused by Bertie. 'We live on our nerves when he's here sometimes' said his mother. 'When he is away I can relax, go to the shops and have a bath relaxed'.

A social worker in one area was concerned by the new local authority short-term care unit being used mainly by middle class parents. ('The poorer parents are more difficult to persuade' she commented.) The hostel was a pleasant old house in a residential area and had once belonged to a wealthy local family. The idea of its use as a short-term care hostel had been well supported by a group of middle-class parents belonging to the local society for mentally handicapped children, and they were apparently making the most use of it. Worried about how to support parents who had a multitude of social problems in addition to their handicapped children, the social worker felt that beds in the hostel should be reserved for what she called 'problem families'. However, it would seem important for all parents of handicapped children, irrespective of social class, to have access to support services; and the social worker's wish to have beds reserved for problem families might be argued against on the premise that a residential care facility for mentally handicapped children should not be regarded as a palliative for problems caused by poor housing, unemployment and poverty.

In some areas the *type of facility* used is related to class differences: middle-class parents refused to accept short-term care for their children when it was only available in old mental handicap hospital, but made extensive use of newly opened local authority hostels or small locally-based health service units which were obviously giving a higher standard of care; whilst poorer parents, with long-standing problems caused by unemployment and bad housing, continued to use the old hospitals which they were forced into using several years earlier by the immensity of their social problems. Some disadvantaged parents continue to use the hospitals because they have grown accustomed to them, but others do so because they 'feel unwanted' in the new hostels which have acquired reputations for being 'classy' and some even think that the new facilities are private and not available to them.

Service planners and social workers often suggest that older parents of very dependent adolescents will be the ones to make most use of short-term care facilities when provided, because they are apparently in particular need of such help. But this supposition was not confirmed by the records of approximately 600 children using short-term care which were looked at during this study. Instead, it appeared that the younger parents of lively* ambulant children aged between six and eight years old were making most use of newly opened short-term care facilities.

One of the reasons why older parents of very dependent adolescents were not using short-term care as much as the professionals had expected them to was because they had not received help earlier in managing their children and over the years had devised their own routines for coping and did not want these to be disturbed. They were not used to being helped and felt unable to cope with the pain of separating from their very dependent offspring and the disruption of life-style that short-term care would cause. Another reason was their lack of confidence in other people's ability to care for their children. After years of coping on their own they were reluctant to relinquish their caring role to strangers, and did not really believe that staff who often looked very young and inexperienced were capable of caring for their children who had difficulties in swallowing food and were prone to fits and 'chestiness'. This lack of confidence in other people was sometimes based on a single past experience when they had let their children go away for short-term care and had received them back with sores or in a dehydrated condition or with coughs and colds. The setting up of a new local hostel did not necessarily restore their confidence in services.

Professionals sometimes do not appreciate middle-aged parents' doubts that their own loving care can be easily transferred to strangers just because a short-term care hostel had been opened. Heavy-handed pressuring of older parents by social workers, care staff, doctors,

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* The description 'lively' refers here to ordinary healthy liveliness associated with any growing child who is curious and wants to play and receive attention. It is not being used in reference to the small group of handicapped children who may be described as pathologically over-active.

teachers and community nurses trying to persuade them to use a residential care facility, seems to devalue the work of those parents who have, for many years, been caring on their own for a very dependent child when, as several older parents remarked bitterly, 'Nobody seemed to care then whether we lived or died or how we were managing'. Young parents who have already started to use short-term care for their multiply handicapped children and have learnt how to find their way around services and have some concept of their right to services, do not have the bitter lack of expectations typical of older parents who never received early help and have consequently built a shell around themselves and are reluctant to use help when it does become available.

The tendency for young parents of children aged six, seven and eight to make more and continuing use of short-term care than older parents who have not had much previous experience of support, might suggest that the very existence of the service is going to create a growing dependence amongst younger parents. Will that dependence increase and lead to even greater demands and eventually result in requests for long-term care, or will each family find their own level of support and fall into a pattern of use to suit their needs without the risk of their children drifting into long-term care?

Although, as referred to above, assumptions should never be made about any one group of parents making particular use of short-term residential care facilities, single parents and those with problems related to poverty and poor housing find the service very helpful.

> Mrs Olf had been living on her own since her husband had suddenly walked out. She was in her late twenties and had two sons. The nine year old boy was physically disabled and the seven year old, Stevie, was mentally handicapped. For two and a half years he had been regularly spending two long weekends every month in the local short-term care unit. He also had additional weeks there during the Easter and August holidays. In a meeting with Mrs Olf she emphasised how the short-term care meant she would keep the boys with her although she was on her own and living in very unsuitable housing. The flat was on the third floor of a block of old council housing stock, built in the 1920s in a run-down area of the city and facing a main road. It was reached by a steep stone staircase and there was no play-space on a balcony or at ground level. The only outdoor space they had was a small grass patch in the front of the flats, and Stevie's mother sometimes took him down there and stood there for a while holding him on a pair of reins to prevent him running into the main road which carried heavy traffic in and out of the city. Mrs Olf said that what Stevie liked about having short-term

> care was 'the freedom to move – he is terrified of the traffic on our road – he loves the garden at the short-term care unit'. For herself, she said 'I can cope if I get short-term care; this way I don't have to send Stevie away for long-term care, do I? Of course, when I'm rehoused I won't need short-term care anymore. I don't really like having it, it doesn't seem right to send him away twice a month does it? When we have a house and a garden things will be quite different for us, much easier'.

Putting the handicapped children of disadvantaged families into a residential care unit situation may give immediate temporary relief, but it does nothing to alleviate the overall problems which have been caused by long-standing social inequalities rather than by the children's handicaps. It is therefore arguable (see also page 28), that giving short-term residential care to the handicapped children of disadvantaged parents is merely using this service as a palliative when more stringent steps ought to be taken to solve the families' broader problems which may have little to do with the handicapped children's needs but everything to do with social conditions, for example, poor housing, low wages, unemployment, inadequate social security benefits. The question is, how far are handicapped children always the major cause of family problems, or do professionals tend to scapegoat handicapped children and sidestep the deeper social issues, and make decisions to separate them from their families when such a decision would never be taken for a non-handicapped child?

Of course, some families will be temporarily relieved by short-term care during a particular time of stress: those with chronic social problems such as Mrs Olf may feel better able to cope with their difficulties because their handicapped child has been taken away for a short while; and others may obtain a feeling of comfort in knowing that the service is available in case of an emergency although they rarely use it. But the blanket assumption that all families with handicapped children can be expected to suffer from some *recognisable and similar type of stress* which will always be relieved by short-term residential care certainly over-simplifies the individuality of families.

It was felt, in the interviews with families, that the stress felt by parents and the extent to which some felt able to cope with very little help whilst others were stretched beyond endurance, depended not only on factors such as the child's type of handicap, the family's social situation, their housing, the number of siblings and ages of the parents, but also on the parents' attitude to crisis and their philosophy of family life. Rather than assuming that because a family has a handicapped child an expected pattern of responses will follow, it would seem more helpful to consider the birth of a handicapped child and his upbringing as a critical life experience for the parents (Burden[1]), the effects of which interact with their personalities and other critical experiences. The event cannot be seen in isolation. The degree of stress, conflict or ability to cope, will depend on past factors in the parents' lives and their experience of coping with other crises.

Bearing this in mind, it would seem essential for every handicapped child to be always considered as a member of an individual family rather than as a member of an amorphous outside group which only needs to be labelled mentally handicapped and given a well-organised residential care service in order to relieve the parents' stress. The study made by Ann Gath into young children with Down's syndrome[2] would support the view that generalisations should not be made about the effects a handicapped child has on family life; referring in particular to marital relationships, she found that whilst a vulnerable marriage was probably put at risk by the birth of a handicapped child, a good marriage was not necessarily marred, and was sometimes even strengthened by the event.

Allowing for individual differences in families, the main reasons why children receive short-term care may be broadly listed under the following three headings:

1 *Because of chronic problems in the family* caused by the long-term illness or handicap of the parents, a sick or handicapped or elderly relative living in the family, more than one handicapped child, poor housing, unemployment, poverty, larger than average number of children, ageing parents, single parenthood, or the father's work taking him away from home. If parents facing one or more of these problems can be occasionally relieved of the care of their handicapped child for short periods, it may temporarily reduce the strain of having to look after him in addition to coping with other difficulties. Such support may also prevent, or delay, the child's admission to a long-stay hospital or some other form of long-term care.

2 *Because of an emergency in the family* due to an accident, the onset of serious physical or psychiatric illness for parents or siblings, the mother's pregnancy, the birth of a new baby, the illness or death of a close relation, the death of one or both parents.

3 *A general need for parents to have occasional or regular support* in caring for their handicapped children, although they may not be troubled by the situations referred to above. Some families may appear fortunate in enjoying good housing and apparent financial security, but they nevertheless require support. Their reasons for having short-

term care may be that they want opportunities to give more time to other children in the family, or want to take a holiday without the handicapped child, or they need regular evenings free to attend an evening class or visit an elderly relative; some may want regular and frequent relief from caring for a child who has serious problems at meal-times and during the night. Some of the parents in this group may be long-term foster parents or may have adopted a handicapped child.

It is likely that the short-term residential care of some of the children in the situations listed in 1 and 2 above may drift into long-term care either in a hospital or in some other setting unless the families' problems are successfully resolved. It is important to remember that short-term care is only a temporary measure of support for some parents, and the policy of using the service as an alternative to solving the families' long-standing problems caused by poor housing, low wages and unemployment is undesirable.

Initiating short-term care

There is no one professional whose responsibility it is to give parents information about what services are available. Any one of the following people may be the first to suggest to parents that short-term care would help them: local authority social worker, general practitioner, health visitor, community mental handicap nurse, teacher, paediatrician, physiotherapist, speech therapist, occupational therapist, a social worker employed by a voluntary organisation such as the Spastics Society, Dr Barnardo's or the local society for mentally handicapped children, a peripatetic pre-school teacher of deaf children, a teacher from the Royal National Institute for the Blind, the officer-in-charge of a local short-term care hostel or a teacher who has an interest in residential care and family support services. Some parents initiate the request for short-term care themselves, having received information about it from their local society for mentally handicapped children. Sometimes a family's need for support is brought to the notice of professionals by neighbours, relatives, voluntary workers, other parents of handicapped children, classroom assistants or the escorts working on special school buses; and any one of these people may be the first to give the parents information about short-term care.

The way in which the information reaches the parents will vary widely from district to district. Some social services departments issue leaflets or advertise the service in health centres, general practitioners' surgeries, community centres and the offices of community health councils; some parents get the information through the news-sheet of their local parents' group; special schools may act as 'postmen', putting into the children's pockets any information sent out by the local authority or health authority, or handing over letters to the escorts on the school buses, although this method of getting information to parents is often ineffective as the letters may get lost on the way home or lie unread in the children's homes. Areas setting up short-term care 'fostering' schemes usually advertise them on local radio and television or in newspapers, the imaginative idea of short-term fostering seeming to have attracted popular advertising methods not normally used by social services departments.

It is vital for all parents to have up-to-date information about services, but there were some parents in the areas visited during the study who knew nothing about what was available, although the local services had apparently been well publicised. It would seem important for local services to be re-advertised at regular intervals in order to reach as many parents as possible and those newly moving into the area.

The ways in which the parents in the study had found out about short-term care reflected local interests, differences and developments. In areas where there were thriving parent groups, or an active parent/teacher association, the information had been obtained at meetings and the parents were generally up to date with new developments. In areas which had a child development centre, the majority of the parents had learnt about local support facilities directly from the paediatricians or from the social worker attached to the centre. The staff of child development centres obviously recognise that they have a role in giving advice and information about local support services and how to use them. It was surprising to note that only two out of 70 parents answering questions about who told them about short-term care said that their family doctors had given them the information, whilst 30 of the 70 said their paediatrician had done so. Perhaps family doctors do not see that they have a role in passing on information about local services to parents of handicapped children, although most general practitioners' surgeries receive leaflets from the relevant organisations concerned for children's services. The 1976 Court report recommended that there should be a general practitioner (paediatrician) in every group practice[3] but this was not accepted. If it had been, perhaps more parents would now be turning to their family doctors for support.

As it is, families tend to lack vital information and help unless they happen to live in an area where there is a child development centre or an active parents group.

Once it is known that short-term care is required, a case conference or meeting is generally held at the hostel or hospital; this may be attended by staff of the local authority social services department, the health authority and education department and any other relevant professionals who know the family. The parents may or may not be invited. This depends on how much the professionals believe in parents participating in decisions about their children. After the case conference the necessary arrangements will be made with whoever is going to provide the short-term care: the local authority, health authority or voluntary organisation. The parents will then receive confirmation that their child will be accepted on certain dates.

Whether or not the parents visit the premises before their child's first overnight stay there will depend on local decisions and the proximity of the short-term care facility to the parents' home. Some will know the hostel and may have been involved in its setting up, but others will be using facilities which are many miles away and they will not have prior visits or introductions to the staff.

After the preliminary arrangements have been made and the child has received a first period of short-term care, there may be no further involvement of the senior social worker or doctor who probably attended the case conference; the child's subsequent short-term care will be arranged between the parents and their social worker or community mental handicap nurse, or directly with the person in charge of the hostel or ward. In some areas a 'middle man' may be involved – an administrator who has no personal contact with parents or staff or children, but who is responsible for the allocation of beds. (The various methods of booking short-term residential care are discussed on pages 46–50.)

When short-term care is used

Demands for short-term care are greatest in school holidays during July and August and half-terms. Some care staff think that the half-term weeks cause them most pressure because all the regular families will then try to use the facility in the space of one week only, whereas during July and August the admission demands can at least be spread over several weeks.

Staff can be under tremendous pressure as they try to satisfy all the parents who need help in the school holidays. They may book in children of all ages and abilities, including those who are very dependent and frail with those who are lively and active and have behaviour problems. In one half-term week a unit with 20 places accepted a constantly changing group of children every day for nine days running. In a typical 24 hours, the facility was accommodating a group made up of: five totally dependent children described as needing 'special care', two very active demanding children, one child who was considered to have a severe behaviour problem, a group of five adolescents who required activities suitable for their age, three very weepy and homesick six year olds, and four non-ambulant cerebral palsied children in wheelchairs who very much enjoyed social activities but needed a great deal of individual physical help in doing anything. This cramming together of handicapped children occurred because the facility had an open door policy and would not turn down any parents' requests for help. But it caused tension for the staff and grave dissatisfaction amongst those parents who feared that mixing large groups of dependent and active children would result in some children not getting their individual needs met, and the younger frailer children being in danger from the more boisterous ones. However, with only this one short-term care hostel having to support as many as 250–300 local families, the staff had to decide whether to try and accept everybody or maintain a rigid code of admission and turn away some families.

A restricted admission procedure is not popular with parents and in some places it results in parents 'shopping around' and using two, or even three, different facilities for their children. One hostel had an admission policy based on not taking more than a certain number or 'mix' of children at any one time, for example, two 'special care' children plus three who were fairly independent and one with a behaviour problem, or two children with behaviour problems and four who were fairly independent. This plan helped to maintain standards of child care because staff energy was not drained and they could give attention to each child. A disadvantage of this admission system was that parents could not always use the hostel exactly when they wanted to, and several of them decided to use the local mental handicap hospital as well, which meant that their children received occasional weeks in the hostel where there was a good standard of child care and occasional weeks in the hospital which had a reputation for poor conditions and shortages of staff. In one district where parents could not use the small local short-term unit as much as they wanted to, some children were going to three different facilities during the weeks of August: a voluntary organisation home, a mental handicap hospital thirty miles away and the local short-term care unit. These continuous changes of environment must have been very unsettling for them and, although one may sympathise with the parents' need for rest which drove them to make such arrangements, this practice of using several facilities is very undesirable.

Most of the parents who were met during the study were very understanding of each other's problems and a few would even occasionally give up their child's August booking to another child whose parents were in greater need of a break. But sometimes there was anxious bickering amongst parents as they competed for August admissions, and accusations that some were taking advantage of a facility or using it unnecessarily or currying favour with staff so as to be first in line for a place.

The way in which a facility was used in 1981 could also depend on whether it was private or statutory and what payments had to be made. Some parents used private or voluntary 'holiday homes' many miles away, sending their children away for two weeks every year and paying fees from £60 a week upwards. Local authority social services departments sometimes helped with payments in approved voluntary organisation Homes, or in hostels belonging to another authority if there was no local unit to help parents who obviously needed a break but could not afford to pay anything. Whether or not the parents paid for using a local authority hostel in their own district depended on the local social services committee's recommendations. After the reductions in public spending of 1981, some parents were charged £7 a week for the use of their local authority hostel which they had been using free for the previous two years. In mental handicap hospitals there were no payments for short-term care as the children were counted as National Health Service patients. When severely handicapped children stayed in a residential setting – hostel or hospital – for more than four consecutive weeks, their parents lost the Attendance Allowance; and a lengthy stay away from home could lose their parents the Child Benefit. But the rulings on such reductions varied according to trends in public spending and the circumstances of individual families.

How short-term care is used

The policy in one hostel allowed a maximum use of 50 per cent of the year spread out in weeks or weekends or single nights according to parents' wishes, but very few of the 300 families using the hostel approached that maximum. The majority of the facilities which were visited did not have any policy with regard to a minimum or maximum time to be allowed in any one year, but assumed that parents would want regular periods of care which would add up to an annual total of something between one month and three months.

Planners and managers of short-term care facilities tend to think that the best way to help families is to give them a break of a week or two very regularly or even as much as one month every two months. However, most of the parents who were met in the study felt that if a service was really going to help them it had to be flexible. By flexibility they meant being allowed to choose the dates of their children's admissions instead of having them decided by professionals, and being able to book at short notice if necessary. When families were allowed to choose their dates they did not usually ask for a fortnight or a month at a time, but preferred very short periods to suit arrangements within the family: for example, the father working late on certain evenings, a sibling having to be taken to a class, the mother having a part-time job in the evenings, the parents needing to visit their own aged parents at regular weekends throughout the year.

Slight but regular short-term care should not be under-valued in comparison with the massive use made by a minority of parents who draw the attention of professionals because their children may have particular problems due to behaviour disorders. The needs of the latter group are important, but their use of short-term care is not typical. More typical, perhaps, is the regular but not very demanding use being made by families who want a firm promise that their children may have occasional weekends or regular mid-week nights.

The children in Table 3 illustrate a common and very popular pattern of using a local short-term care unit when the planners and care staff permit flexible and slight use which is geared to the individual requirements of families. The way in which these families used the unit remained fairly stable for a number of years, they felt happy with the support they were receiving and had no wish to increase their use – indeed, they felt uneasy and threatened when social workers, community nurses and teachers suggested they increased their use. Their greatest worries were that the regular support they so much

Table 3 A common and popular pattern of short-term care

The children and families	**Pattern of using short-term care**
Pamela: an only child aged 11, very dependent on others for her care.	Two nights once every fortnight since the age of 9.
Doris: aged 12, totally dependent on others for all her care. Has 2 brothers.	One night every week since the age of 11.
Hilda: aged 12, very dependent on others for her care. An only child.	Receives two separate nights every month since the age of 10, so that her parents can go out for an evening together.
William: aged 15, an able and independent boy, the eldest of 5 children. The mother suffers from a chronic mild depression.	Since the age of 12 has been receiving one night every week and a fortnight every July.
Betty: aged 16, totally dependent on others for all her care. Four other children in the family.	Since aged 13 has received one night every week. It was supposed to stop when she reached 16 but she was kept on for an extra six months.
Harry: aged 16, fairly independent. Has a younger brother. Mother on her own because of divorce.	Had one night every week from age 14½ to 16. Stopped at 16.

appreciated was going to be cut off when their children reached the age of sixteen.

Some professionals fear that families will abuse flexibility, informal bookings and the use of the facilities according to their individual needs, but this does not generally happen. Referring to the support offered by Honeylands, Gillian Pugh and Philippa Russell wrote:

> 'Honeylands is always open and available as a refuge. The availability of short-term care "on demand" has not been abused and has been found to serve as a major resource for parents of young handicapped children. The general atmosphere of the unit is one of a large extended family and as in the extended family, parents can determine their own need for "shared care".'[4]

A few parents who were met in the study did not want too much flexibility because they found the separation from their children extremely painful. They preferred to have a rigid timetable of dates predetermined for them by the professionals and in this way they felt less responsibility for the decision. Two of them said:

> 'We hated the idea of short-term care but it was more or less arranged for us and we agreed to it.'

> 'They give us the dates and we stick to them and make our arrangements for holidays and evenings out to suit *their* dates.'

Having dates arranged by the professionals also seemed helpful when there were disagreements between a husband and wife about using short-term care; some mothers felt more able to absolve themselves from the decision to send the child away if they could present the father with dates decided by a professional.

A senior member of one unit said, 'Many of the parents *need* a pre-arranged plan, without it they would never ask for help'. This particular unit had a good reputation for parent support and the staff believed that there was a need to 'sell' their services to some parents rather than wait for them to ask for help.

However, such a policy requires staff who are sentitive to parents' needs and there is a big difference between what those particular staff saw as *advising* parents and the more crude pressuring of parents to use a service in order to keep the beds full as was happening in some places (see pages 58–64).

The freedom of choice described by parents as flexibility is more subtle than just suiting a family's convenience. Short-term care purports to be a family support service, but often creates confused and ambivalent feelings for the parents and it is important for them to feel still in control of their children's lives. Being able to make their own decisions about short-term care is one way of *not* losing control.

There were some parents who hardly made any use of short-term care and they would not have dreamed of having a forward planned timetable of bookings. But they felt supported in merely knowing that the service was available if they should ever need it. 'We hardly use it, we don't want to, but it is good to know that if we pick up the phone they would say bring him in.'

Parents making minimal use of short-term care often tended to be older parents of very dependent children who had managed for many years without help and were reluctant to use a residential service as it seemed like rejecting their children – an idea which they had been avoiding for many years. (See pages 29–30 for earlier reference to older parents.) However, beset by the common worries of older parents of handicapped children—what would happen if the father had a heart attack or if elderly grandparents were suddenly ill—they wanted the reassurance of knowing that there was somewhere locally which would respond to the request, 'Please take our child for the night because something awful has happened in our family'. They dreaded that in an emergency their child would be taken to a hospital or Home which they had never seen; so some were using a residential facility just once or twice a year to reassure themselves that their children knew the place in case they ever did have to be admitted.

It may be difficult for service planners and managers to appreciate the benefit of minimal use of short-term care, for example, one night a year, one night a month or just 'knowing it is there'. Massive use seems a more tangible proof of the usefulness of the service and a justification for the financial input by taxpayers. In 1980 a well-used hostel of 20 beds was costing its local authority £170 a week for each child, while an under-used one of similar size was costing as much as £500 a week. Such figures should provoke questions about what *type* of short-term care services ought to be set up instead of how to persuade more parents to use the under-used hostel. Should plans always concentrate on providing traditional 15–20 bedded hostels and specially upgraded short-term care wards? Is this what parents want and what their children should be fitted into? Do planners know what families want and is it possible to close the gap between what planners think parents want and what they actually find most helpful? Twenty-bedded hostels are expensive to maintain and they need to be kept full in order to justify their costs, and at very busy times there is enormous pressure on staff and perhaps a drop in standards of child care. In contrast, foster family schemes, day care and sitting-in services, can be used as required, are popular with parents and have the advantage of the financial input being invested in direct care staff instead of being wasted in maintaining half-used buildings. (See Chapter 8 for discussion about fostering.)

An 'emergency bed' or developing a concept of reassurance?

Planners and staff sometimes refer to an *emergency* bed for use in family crises as an essential part of a good support service. It may be in a local short-term care facility, but sometimes it is in a mental handicap hospital a long distance from the family home and is the only support available. It is arguable that the concept of an emergency bed is not ideal in planning a family support service, for it seems to accept that some children will probably have their first experience of residential care in the middle of a family crisis, without them or their parents having any preliminary introductions to the facility and the staff.

Parents are made anxious and depressed by services which are confused or non-existent until an emergency arises. Ideally, from the first day their child is diagnosed as having a handicap, or from the day that a family moves into a district, they should have a set of expectations (reassurances) regarding the local support that will be available to them during periods of quiet *or* at times of crisis. They need the reassurance of knowing that services are there which can be used in a variety of ways at the various stages of their child's development – pre-school advice, short-term residential care, day care, further education and adult training centres. Unfortunately, however, most plans get made ad hoc with no firm philosophy behind them beyond the provision of a few regular short-term beds and an emergency bed for times of crisis, and these will quite often be tacked on to already stretched long-stay services.

The *concept of reassurance* as a form of family support should be recognised as a valuable part of any short-term care service. The feeling of 'knowing help is there we are relieved though we never use it' can give a sense of security and may help to prevent family stress and breakdown. If the concept of reassurance were successfully developed, then it would expect *all* families to be known to staff of local services and all parents to be familiar with the services that are available and to have had advice on how they may be used and some initial introductions, even if they are not yet wanting to use them. To aim for *reassurance as a concept*, rather than emergency provision, might seem like playing with words, but it is important as an aid to developing a positive philosophy in service planning which will not only meet the needs of families but also have regard to how parents and children feel about the services that are being provided for them.

Recording the use

It was found during the research visits that, although the actual times that parents used short-term care were recorded, their individual patterns of use were not being sufficiently analysed by care staff, managers and planners. It would seem important to monitor the use very carefully, as there was evidence that some children's time in short-term care was gradually increasing, but it was only when it became obvious to staff that these children were drifting into long-term care that any steps were taken to discuss this fact with the parents and other professionals. Constant checks are needed to see if the ways in which families are using the facilities are in the best interests of the children (see Chapter 4 pages 106–107 and Chapter 6 pages 179–180 for further references to children drifting into long-term care).

The need to be locally based

If a short-term care service is going to be flexible, familiar to parents and children and based on a philosophy of shared care and reassurance, then it has to be *locally based.*

> 'I can put up with the separation because the unit is only just round the corner so I can go round and put him to bed myself.' (Mother of a five year old, totally dependent, cerebral palsied boy.)
>
> 'It's local, that's why we like it, the kids can still go to their own schools as usual. When we had to use the hospital it was twenty miles away and they had to miss school every time.' (Said by parents at meeting, soon after the opening of a locally based unit.)

The 1974 Harvie report referred to the anxieties of parents whose children were going to facilities which they (the parents) had never seen:

> 'Many mentally handicapped children who normally live in their own homes are placed each year by local authorities for short periods, generally of a few weeks, in homes, hostels, hospitals or occasionally foster homes. This sort of arrangement may be made to help over a family crisis or simply to allow the family to have a break from the strain of caring for a handicapped child . . . Although the child is only from them for a short time we have heard of parents who became anxious because they have not seen the place where the child is to stay or met the people who are to care for him. We think that these anxieties should be respected and that, where possible, parents should be given the opportunity of seeing the establishment.'[5]

The advice of the Harvie Committee has not been heeded. A 1979 survey of services for mentally handicapped children in the Greater London area referred to 27 private or voluntary homes being regularly used for short-term care, some being as far away as Dorset, Hampshire, Lincolnshire and Worcestershire.[6] This situation is not uncommon. One of the voluntary organisation units visited during this present study, with places for 15 short-term care children aged two to 16, did not serve local parents but took children from eight different counties covering an area of approximately one hundred miles north, west and south. Between 200 and 210 children were going through this unit each year in the late 1970s, most staying for two to three weeks but some for as long as six weeks. Very few parents could manage the long journey to the unit. The children were transported there and back by social workers and there was no contact between families and care staff. The officer-in-charge maintained links with the parents over the telephone. She said she wished she 'had time to visit families but they all live too far away'. She had seen only six parents in their own homes out of the total of 210 families who used the unit. The children did not go to school when they were having short-term care and there was no trained teacher on the staff. It was deplorable that the social service departments of those eight counties should have sent their mentally handicapped children so far away from home for short-term care; it was not only a poor practice in respect of child care principles but it was also a very inappropriate form of family support. Parents *want to be involved in their children's care*; this point was made continuously by those who were met during this research, and to enable that involvement means providing local services.

In one locally based short-term care unit, run by the local health authority, 67 of the 72 families making regular use of it lived within six miles, and 17 of these were within walking distance. Only one of these parents expressed a preference for a more distant service. This was a father who was within walking distance and said it worried him when he went to the local shops to realise that the child was so near but not being looked after by his own family. His remark was unusual. In all meetings with parents it was common for them to emphasise a wish for locally based services.

Rosemary Evans and Gurli Fyhr, describing a Swedish short-term care service, stressed that much of its value came from it being locally based:

> '. . . the local borough was persuaded to provide finance for a short-stay home . . . It was to be in two ordinary flats on the ground floor of a new residential estate, consisting of low blocks of flats accommodating families of varying sizes. Throughout the county of

> Ostergotland it is usual to find ordinary baby clinics, toy libraries and other services housed in the flats or houses of the areas they service . . . A large part of its value lies in the fact that it serves a local population. This makes it possible for parents to drop in and the children attend their own schools and this must reduce some of the anxiety and upheaval associated with allowing someone else to care for your child.'[7]

When short-term care starts being provided locally there is an increase in the numbers of parents using it. When one borough had a scheme whereby children were booked into voluntary organisation Homes outside the borough (some as far as a 100 miles away) only 25 families used the scheme. But when that borough decided to have a different scheme and opened a locally based children's home of six beds and set up a 'caring family' service (local short-term 'fostering') as many as 77 families came forward for help.

The increasing number of families using short-term care when a service is set up locally may be explained, of course, by the mere fact that its coming into existence has exposed a need. It may also be explained by professionals canvassing for the newly opened facility to be well used, and by local publicity about its opening. And if the parents themselves campaigned for the facility to be set up they will be determined to make good use of it. However, whatever explanations may be postulated for the popularity of locally based units as opposed to distant ones, the parents unquestionably found the opportunity they gave for sharing their children's care eminently preferable to the total separation caused by using distant units.

Parents naturally get very worried about giving their children to other people to look after and not seeing what is happening to them. These worries can never be wholly prevented but they may be lessened if a unit is local and also gives parents some opportunities to be involved. A single mother with two very frail handicapped boys, using a facility which was within walking distance, was able to get herself and the boys accustomed to the idea of residential care by going round to the unit and putting them to bed herself. She said she would never have used short-term care if this local unit had not opened. She wanted to share the experience with her sons, and not have them totally separated from her. Both boys had a deteriorating medical condition in addition to their mental handicaps and have since died. The mother was comforted by being able to share their care in a local unit and she was not left with sad memories of having sent them away to an unknown facility.

Locality of the units is a major influence on the *pattern of use*: parents using locally based units are more able to develop flexible, and perhaps even drop-in, patterns of use and have very short periods of care (one or two nights); whereas families using distant facilities tend to have rigidly arranged longer periods booked for them, for example, regular admissions of two weeks every six weeks, or even a month in and a month out for a year ahead. The organisation of transport also affects the use: children going to units a long way away obviously have to stay a week or more instead of just one night, because of the long journey.

The lengthier stays in more distant units are often explained as giving the child 'treatment' or 'an assessment' or 'putting him on a programme', whilst very short periods of care given in local units according to parents' wishes may be regarded as a less valuable form of help. Perhaps this is because residential care is not yet widely recognised as a professional service in its own right, requiring many skills in child care and family support. However, there is no reason why a locally based unit offering very flexible and short periods of residential care cannot also have an input from specialist professionals. This happened at Honeylands as early as 1973; the parents could use flexible short-term care according to their wishes as well as getting advice from a variety of professionals (see pages 14–15).

Some of the advantages of having a locally based unit are listed below:

1 It enables the handicapped children to stay in their local neighbourhood.

2 The parents and children, siblings and relatives, can visit and get to know the staff.

3 Parents can help with the care of their child if they wish, so they seem to be only partially separated from him.

4 Parents may not have to rely entirely on transport provided by statutory services, or on public transport, in getting themselves and the children to and from the unit.

5 It may be used for occasional day care or odd-hour care, for example, while the parents are shopping or have a dental appointment.

6 It will probably serve the one or two special schools attended by the children, so they know each other, and their parents are likely to be members of the same parents' group.

7 The children are able to continue going to the same school. A more distant unit means they have to be absent from school or fit into an unfamiliar one.

8 Parents may be able to take an active part in the management of a locally based unit.

9 It allows for flexible short periods of residential care, single nights, mid-week and weekends, whereas a more distant unit means long stays of at least a week because of the journey.

10 As parents are more likely to know the staff of a local unit, any problems that arise may be promptly tackled (although of course there are still problems of parents getting to know the staff adequately, no matter if the unit is distant or locally based; for particular reference to this see Chapter 5, especially pages 118–128).

Booking-in procedures

Booking the dates for their child's short-term care can be a sensitive moment for parents and should be handled with understanding so as not to increase their ambivalent feelings about the service. The act of booking in their child for short-term care means that parents are having to recognise their own difficulties in coping with their child and admit the need for help; and accept that the help means sending the child away; and re-affirm their child's handicap, because the use of a special service not used by non-handicapped children is emphasising yet again that their child is 'different'. The ways in which parents can get their children booked-in vary according to decisions made by the local professionals. The following are some methods noted during the research.

1 *Through social workers.* Parents already known to the social work department could telephone their social worker and make the booking, or it could be arranged during the social worker's visit to the family. Not all families using short-term care were receiving regular visits from social workers and after the initial visit to establish the fact that the family needed help and the case conference agreeing to the child's admittance, the family might not have a social work visit for many months or even a year; subsequent bookings could require nothing more than a telephone call to the local social work offices.

2 *Through community mental handicap nurses.* These nurses were usually based at a mental handicap hospital but tried to work closely with health visitors and social workers. Some parents described the community nurses as 'better than social workers' because they had had training and practical experience of working with people who were mentally handicapped; also, if the children's short-term care was being

provided in the mental handicap hospital, the community nurses generally knew the ward staff and the parents liked this link.

3 *Through the social services department offices* via what was sometimes called the 'bed bureau'. This was a section of the department run by an administrative officer or senior social worker who had overall responsibility for all residential care services in the borough or city (for ordinary children, homeless people, and elderly and physically handicapped and mentally ill people). Parents needing short-term care for their mentally handicapped children could book via the bed bureau if they were known to a social worker and were already on the list of the social services department hostel. If they tried to book directly with the hostel staff they would be told that this was not permissible because it had to be arranged through the bed bureau. This cumbersome third party method of booking created unnecessary distance between care staff and parents.

4 *Through a hospital administrator in the hospital providing the short-term care.* The bookings were arranged for a year ahead and a list of dates then given to the parents. The hospital which had this system had community nurses but neither they nor the ward staff were permitted to do the bookings.

5 *Through a consultant psychiatrist in a mental handicap hospital.* In one area a doctor said he must decide on every short-stay care admission even if a child had already received several admissions and was known to the staff. This method had the disadvantage of delaying bookings because the doctor was frequently away at meetings and conferences, and so was not available to agree to the admissions. Also, he did not know the children and parents very well. The community nurses and ward sisters thought they should have been given responsibility for the bookings as they were on the spot all the time and knew the children and parents.

6 *Provisional booking through hostel staff,* who then had to query the request with the social services department and telephone back to the family to say whether permission had been given. Like the bed bureau, this created distance between the care staff and the families they were helping.

7 *Through the care staff.* Parents would telephone or visit the unit to ask for the dates they wanted, and these would then be agreed or another date suggested that might be mutually satisfactory. This method encouraged contact between the care staff and families. It was generally the two or three senior members of the staff who did the

bookings rather than one of the junior members, although in some facilities the junior members could take provisional bookings if the seniors were off duty and these would be confirmed as soon as possible.

The last method, that of booking directly with the care staff, was the most popular with parents and staff. The majority of care staff wanted to take responsibility for organising their own bookings and they felt resentful when opportunities to organise admissions through direct contact with parents were taken from them by administrators or social workers who did not know the children.

Although booking-in procedures are so important and reflect the philosophy of the facility and the attitudes of care staff, the decision to have one or other method of booking is often based on very arbitrary reasoning. One local authority may agree that a method of direct booking via the hostel care staff will cause no problem at all and is best for the families, but another will decide that such a method is impossible and would be 'confusing for staff' or 'encouraging parents to take advantage'. The latter opinion illustrates traditional attitudes towards clients who require residential care: some professionals are so accustomed to residential care services being used by persons who are not encouraged to make decisions about their own care and who are thought to need protecting, directing or censoring (children in care or trouble, confused elderly persons, homeless families) that they find it difficult to permit flexible arrangements for parents who have mentally handicapped children and who expect to have some choice about how they are going to use residential care.

The rationale behind third party bookings seems to be based largely on keeping control of care staff and families and lessening the likelihood of a close relationship developing between them which could create more demands on services. The senior social worker in one area said, 'If we allowed care staff and parents to do the bookings between them the whole thing would soon be out of control'. But in areas where it *was* allowed the system did not seem to be out of control. In a hostel with 200 families on its list the bookings were made by care staff, and within two years of the hostel's opening the parents' requests had settled into a fairly even pattern: one-third making minimal use, one-third having regular care in a pattern of one or two nights every fortnight or one week a month, and the other third making more demands but by no means creating difficulties for the staff. In the last group there were approximately six parents who were likely to make excessive and sometimes unreasonable demands, but the staff managed to control the situation.

A senior social worker who was responsible for one local authority short-term care hostel required the officer-in-charge to always tell her first about requests from parents and she then took responsibility for the final decision. She said that her reasons for doing this were: 'More timid parents would be over-ruled by the more demanding ones'; 'Some parents would manipulate the staff'; 'It has always been done this way in all our residential homes in the district'; and 'My staff need protection from parents, and if they do not want a child but don't like to refuse in case the parents get upset, then they can say I made the decision. It is better for me to be unpopular than the care staff'. She believed that it was important for parents to have somebody to blame if they could not get their children in, and better for care staff to scapegoat a senior social worker than take responsibility themselves for refusing any bookings.

Control of bookings by a third party may seem to be a way of 'protecting' staff but it prevents the flexibility and growth of mutual trust between care staff and parents which is vital if a philosophy of shared care is to be developed. The provision of short-term residential care for mentally handicapped children requires mature attitudes and sensitive understanding of family needs, and it might be argued that if care staff are mature enough to take on the very responsible task of caring for other people's children they should also be able to manage the bookings which are an integral part of the whole service.

A major advantage of direct bookings with care staff or nurses is that the staff and parents can have an opportunity to talk to each other about the child and his reactions to the short-term care. The parents in one area said that one of the nicest aspects of short-term care for them was that whenever they rung up the hostel they were always answered by a reassuring and welcoming voice at the end of the telephone and were able to talk about their children.

However, even when there were direct bookings, some parents did not always meet with as good a response as they had hoped for: 'They always sound so gruff when I ring up . . .'; 'They do not sound very welcoming'. It is very important for parents to feel that their child is welcome, but some detected a stifled groan at the end of the telephone as they mentioned their name. This was very hurtful. When parents make requests at very short notice their decision has most likely been precipitated by a stressful episode with the child, or other members of the family, so the way in which professionals answer the telephone and respond to the request will be crucial in either reassuring them or increasing their stress. A warm response re-affirms that the staff enjoy having their child and want to help. (For further reference to this point see Chapter 5, pages 126–127 and in general throughout Chapter 5.)

Sometimes parents were discouraged and upset when they telephoned for short-term care in a hospital because they were unable to contact the familiar community nurse or any of the ward staff. They would have a long wait while the community nurse or sister was 'bleeped' and they were sometimes put through by accident to another department altogether: 'I telephoned the hospital three times and each time got put through to the laundry department, so I was in a real state after half an hour trying to get some sense into the switchboard, and it put me right off ever asking for help again' (mother of a nine year old boy with Down's syndrome). Such experiences may be described with wry amusement later on at parent meetings, but they are nevertheless very upsetting.

As the booking-in procedure is such an important aspect of the service and an influence on developing positive links between the parents and children and staff, it would seem advisable for the staff and managers of all short-term care facilities to regularly review their procedures and consider if the way they do it is really helping families and encouraging good relationships. They may ask themselves the following questions:

1 Who decides on the procedure?

2 Is the procedure written down and explained to all members of staff and discussed with new members?

3 Have staff had opportunities for reassessing the procedure and changing it if necessary?

4 Do staff have any information about how parents feel about the booking-in?

5 Do staff and parents have opportunities to discuss the procedure together and consider how it may be improved?

6 Do staff know how other facilities manage their bookings and, if so, how these compare to their own?

7 When parents telephone to request a date, is care taken to make them feel that their request is reasonable and their child welcome?

8 Are staff aware if parents prefer to be answered on the telephone by any one individual more than another and, if so, what do they think is the explanation for this?

9 If a refusal has to be made because the facility is fully booked, do the parents feel that the staff are genuinely sorry that they cannot help this time?

Summary and conclusions

Whilst some families, because of special circumstances, may make excessive use of short-term care, it should not be assumed that use depends entirely on the degree of the handicap, age of parents, social class, or size of family. There are *wide variations in family needs*; and the various strategies that parents use to cope with a handicapped child and the degree of stress they feel and their use or non-use of available services will relate as much to the family life-style, past experience, parent personalities and reactions to life crises, as to the degree of their child's handicap.

Methods of *getting information* to parents about short-term care facilities are very inconsistent. It depends very much on local developments and the interest and enthusiasm of individual professionals who want to be involved.

When short-term care is used depends as much on what is available and the units' criteria of admission as on the individual needs of families. It also depends on the willingness of staff and managers to be *flexible*; unfortunately, the more supportive the staff try to be the more difficult it becomes for them to turn away families who need help, and when they try to meet everyone's needs they sometimes find that their standards of child care are deteriorating.

The development of a *concept of reassurance* rather than the mere provision of 'an emergency bed' would be an aid to developing a more positive philosophy of services.

Record-keeping is not as good as it should be. A careful analysis of how parents use short-term care could define local needs and families' opinions of services and thus assist with future planning.

Short-term facilities must be *sited near* where families live so they can be used flexibly and be familiar to the children and parents and cause as little disruption in the lives of the children as possible

Booking-in procedures need to be carefully thought out as they are crucial in developing or marring parents' confidence in services and in developing contact between parents and staff.

Short-term care should be available as required as part of a packet of services which families can *choose* from. Ideally, each district should have a variety of support facilities which families can use as they wish and according to their changing needs. A good support service in every local district should include (a) four small short-term care homes of not more than five places in each, providing flexible day, residential and evening care; (b) a group of short-term 'foster' families; (c) a system of sitters to go into parents' own homes; and (d) ample play-schemes during the school holidays.

Residential short-term care is not necessarily the answer to every problem. Indeed, it may even increase, or cause, stress in families. This is discussed in the following chapters.

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3 Family reactions to short-term residential care

Some general aspects of short-term care were briefly discussed in the previous pages; who uses short-term care, why and when, the need for flexibility, the question of emergency beds, the importance of locally based services, and booking procedures which will promote positive contact between carers and family. The following sections, using material from the informal interviews with parents and the visits to units, refer in more detail to what parents thought about using short-term care, their initial reactions to the idea, specific worries, pressures on them to use it, and the feelings of other members of the family about the handicapped child going away.

Initial reactions to the idea of having short-term care

It may be assumed that parents will respond eagerly to the idea of short-term care. However, more than half of those met in the study described having feelings of uneasiness when the suggestion was first put to them.

> 'I was a bit horrified.' (Mother of a two year old, cerebral palsied girl.)
>
> 'I thought I'm not putting him *anywhere*, no *thanks*.' (Mother of three year old boy described by social workers as 'over-active'.)
>
> 'We felt wary.' (Parents of nine year old boy with Down's syndrome.)
>
> 'I was dubious about how he would settle.' (Father of 12 year old.)
>
> 'I had mixed feelings: relief at the thought of a break but distress at the idea of leaving her.' (Mother of a four year old.)

These remarks were typical of parents' initial reactions to the idea of short-term care. Their uneasy reactions did not differ noticeably according to whether it was a local authority hostel or a health authority hospital that was being suggested. The idea of short-term fostering with another family provoked even more wariness; only one of the nine parents using short-term fostering felt relief at the idea of it, the other eight had been very uncertain. It was common to find that parents had an initial mistrust of short-term fostering. They were confused about the legislation, often thinking that short-term fostering meant they would lose their rights to their child, and they doubted whether another family could cope with their child and were suspicious of their motives for wanting to try. However, after experiencing fostering there was overall satisfaction and fewer complaints about the quality of care than from parents who were using more traditional forms of help, for example, hostels or hospital wards. (Chapter 8 discusses short-term fostering.)

Specific worries

One hundred and seventeen parents answered the question: 'What worried you about the idea of short-term care?' Thirty-three said they could not name any worries but the other 84 were quite definite and each listed a number of practical and/or emotional worries, some giving three or four examples. Forty-nine described worries about their children's practical day-to-day care, management and comfort—their mealtimes, whether they would be cared for properly during the night, how their communication problems would be managed, whether they would be safe, if they would be hit by other children or ill-treated by staff or get into some sort of danger such as swallowing an object or running out and getting lost; for example:

> Mrs Yardley was worried about whether her daughter would run with a fork; she was active and had a habit of leaping up in mealtimes and running about the room holding her fork near her face.
>
> Mrs Keats was worried about her severely cerebral palsied child choking on her food unless fed in a certain way, and she did not feel that the staff had actually acknowledged that they were aware of this danger.
>
> Mr and Mrs Rangot were worried about their son getting out and running away, and they were not sure how much security there was at night.

Fifty-one parents described worries specifically connected with the emotional aspects of separation: the actual *moment of separating*; the difficulties of coping with their own guilt feelings about sending their child away; worries about their children being unhappy and homesick or thinking they had been sent away as a punishment; the likelihood of their children losing their love for their family because of the separation. The sentiments expressed by the following four families were common.

> Mr and Mrs Crittle's son, 15 year old Peter, was very severely handicapped due to a virus infection causing brain damage when he was a baby. He was the youngest of two boys. His parents described themselves as very lonely without him and worrying all the time about how he felt about the separation. 'It's not right to not have him here with us. We're a proper Darby and Joan without him, just ourselves in the evenings; and he's bound to feel homesick even though he cannot talk', they said.
>
> Mr and Mrs Baker's daughter, Jenny, was five years old and severely mentally handicapped and over-active, exhausting her parents and older sister by her ceaseless energy. But, despite their difficulties, they loved her dearly and felt very distraught about having to use short-term care. They said what they dreaded most of all was that they would lose their love for her and learn to do without her if she went away too much, or that she might lose her love for them. 'How awful it would be if one day we had her in the hospital for short-term care and we walked in and she did not come to us because she did not love us anymore. We are frightened of being glad that she is away and frightened that we will all grow away from each other', her parents said. 'The further away the unit is—we used to use a hospital fifty miles away—the more risk there is that we will grow apart', said Mr Baker. 'That's why we are glad that the local place has opened. But even so, the separation is still hard to take'. His reference to the importance of a locally based unit bears out what was said in Chapter 2—the necessity for good contact between parents and staff.
>
> Mrs Hamish said that she thought the benefits of short-term care were almost cancelled out 'by the distress of leaving my daughter and the week's separation'. Her little girl was three years old and had Down's syndrome and a weak heart.
>
> Mr and Mrs Taylor's son was six years old and severely multiply handicapped, unable to walk or speak or feed himself. 'Will they understand Maurice's little ways I keep asking myself all the time he is away', said his mother. 'I feel so guilty about leaving him there, it is as if a part of me goes when he goes for short-term care. I just hate the mental worry of having him away from me and not in his own home.'

Sometimes *one* of the parents would find the separation particularly difficult to face so would leave the other one to take the child to the unit: 'Dad can't face it so I always drive her there' said the mother of a seven year old girl with Down's syndrome. But sometimes both the parents found the separation so painful that neither was able to face the stress of getting their child to the short-term care unit and therefore arrangements would be made for the child to be taken in by a social worker or go straight from school on the school bus.

Most of the *practical worries* did not actually get fulfilled and they lessened over the months that the facilities were used. But this was due to time and use creating a sort of confidence rather than the units having a carefully thought out policy of giving reassurance through explanations about the organisation of care. Time and use are important factors in parents gaining confidence in a support service, but minds would have been eased more swiftly if there had been opportunities to discuss worries with residential care staff and social workers in the initial stages of deciding to use short-term care. And it was very disquieting to note the tendency for the parents' *emotional worries* to be almost totally ignored by all grades and disciplines of staff.

The existence of the initial worries appears to have particular implications regarding short-term care policies, management of units and staff/parent contact. None of the units visited were entirely meeting their responsibilities in a manner which would prevent or ease parents' worries. The professionals seemed to think that the basic fact of having provided the service was sufficient in itself and that there was no need to also think through a *constructive policy of family reassurance.* Even allowing for the fact that some of the worries would be difficult or even impossible to assuage, little was being done to ascertain or recognise their existence as a serious concern of service policy; so parents were not clear about *who* would see that their children did not fall out of bed or the *actual precautions* that would be taken to prevent them breaking glass, or if staff *really understood* that their child did not like some particular item of food. They may have filled in forms with the social workers, listing their children's dislikes and likes and routines at home, but they had no firm assurance that anybody was accountable for acting on the information. Indeed, in some units the direct care staff did not make any use of the forms so trustingly filled in by parents. (See page 140 about parents filling in forms.)

Worries about the practical care of the children and the emotional aspects of the separation were less apparent amongst those parents using Rivermead (the social services hostel) than those using Collingwood and Field Lodge (health service facilities). This seemed to be due to the Rivermead parents being better prepared for the idea; they were members of a very active local society for mentally handicapped children and had shared an interest in the setting up of the hostel, and the officer-in-charge had done preparatory work in the neighbourhood by introducing the idea of short-term care to parents prior to the hostel's opening. Another big advantage was that the hostel was sited in the local community in an ordinary street and parents were able to go in and out of it informally. The local special school teachers also had good links with it and took an interest in the children staying there. In contrast, the health authority units, although similarly serving local communities, did not have the same degree of parent contact, the special schools were not involved and the fact that the units were on large health service sites, which also accommodated sick people and general hospital facilities, seemed to give the parents a feeling that their children were not having community care but were hospital 'patients' and out of their control.

The worries of the parents using health authority units were justified in so much as the care was not so child oriented as in the local authority unit; the staff had fewer qualifications and experience in caring for children and were not encouraged by senior staff to use their initiative and work at developing positive contacts with parents. The extent to which the parents' worries were fulfilled once they had begun to make regular use of short-term care is discussed in the section on dislikes (see pages 87–98).

It was plain that their worries did not relate entirely to the nature of the children's handicaps but were typical of the anxious reactions which might be expected of any parents whose children are going away from home for a few nights—a normal wish to protect them from a strange experience and to continue caring for them, a recognition of the importance of preserving family relationships, a concern for their children's vulnerability and dependence as *children*—these issues had little to do with the nature of the handicaps and much to do with the normal feelings of any parents about being separated from their children.

The normality of parents' worries about their children's absence from home was not sufficiently acknowledged by the professionals, either amongst themselves or to the parents. The fact that the children were handicapped seemed to obscure professionals' expectations and recognition of parent worries, especially their emotional worries about the separation. Sensitive issues such as the children being homesick and the parents being grieved at the parting were not acknowledged in the same way as they might have been for ordinary children. Indeed, the study showed very clearly that handicapped children are not only more likely than ordinary children to have numerous early separation experiences, but that the emotional impact of these experiences on them and their families is not considered to be as traumatic as for ordinary children. (There are many references to this point throughout this study, particularly in Chapter 4 pages 95–98, Chapter 5 pages 128–149, and the whole of Chapter 6.)

The discussions with parents pinpointed the following deficiencies in the provision of short-term care services.

1. Parents of handicapped children experience all the normal worries about separation that one would expect to find amongst parents of ordinary children, but the normality of these worries may not be acknowledged by the professionals providing short-term care services.
2. Parents had little or no opportunity to discuss their worries related to their children's special needs as handicapped children, and although they sometimes filled in forms about their children's care, they were not certain how and if this information was used.
3. Professionals tend to underestimate the love that parents and their handicapped children feel for each other and the painfulness of their being separated.

Putting pressure on parents

The way in which short-term care is put across to parents always emphasises how nice it will be for them—they will be able to have a rest, take a holiday, paint the house, mend the car, take the siblings to the zoo—they are not expected to worry over much about the separation experience or want to be visiting the mentally handicapped child when he is away in short-term care. The whole point of the child's absence is that it will be a pleasure for the parents. Any trauma that may result from the separation, for the parents or the child, is likely to be strenuously denied. This is the reverse of attitudes regarding separation experiences for children who are *not* handicapped: parents of ordinary children going into hospital because they are ill are encouraged to visit them as much as possible and the work of Bowlby, the Platt Report and the films of James and Joyce Robertson point out the dangers of badly handled separation experiences (see Introduction).

Some of the professionals met in the study lacked sensitivity to parents' normal feelings about separation and put considerable pressure on them to use short-term care services. They emphasised the advantages of the service—the child would be comfortable and well-cared for while the family had a welcome break and the siblings would be able to do all the things they could not do when the handicapped child was at home—but the emotional aspects of the separation were virtually ignored, such as how the parents would cope with making the decision, their missing the child, and knowing that he would probably miss them, and wondering whether he would understand why he was being sent away. Emotional worries tend to get swept aside by professionals who are very enthusiastic about the idea of separating the child from his family and the relief they think this will bring.

It was found that even if it was unit policy to introduce the families to the facility before the children actually had their first overnight stay, this preliminary visit rarely gave parents an opportunity to discuss the emotional aspects of using short-term care, because it would concentrate only on the physical aspects of the service: parents would be shown the bedrooms, the playroom, dining room, garden, pool, colour television and kitchen. The physical environment is, of course, an important integral part of the whole service and the parents should be able to see where their child will sleep, eat and play, for this helps them to visualise him there and can reassure them that he is welcome and comfortable. But the introductory visit should also give parents a chance to ask those questions which are uppermost in the minds of so many of them – for instance, 'How much will he understand about why we are sending him away?', and, 'Will he miss us?'.

There often seemed to be a conspiracy of silence over the emotional aspects of short-term care. The insensitive advice of one social worker typified the common denial of feelings: 'When he's there, forget about him completely and enjoy yourselves'. Families were told very plainly that they were not supposed to sit at home missing the child, nor were they supposed to visit, as the whole purpose of the service was to separate the child from the family. The knowledge that they are supposed to enjoy the absence of their child may make parents deny their feelings of loss and collude with professionals in a make-believe of enjoying themselves. It is not unusual for parents to put on a charade of enjoying themselves to please the social worker who arranges the short-term care. Some of those met in the study said that they not only felt guilty about sending their child away but guilty at not really enjoying his absence as much as the professionals expected; for example:

> 'I knew the social worker wanted me to feel grateful, but I didn't—that made me feel even more guilty about the whole thing.'

> 'I didn't tell the community nurse we had a rotten time—she expected me to be glad that I'd put Tom in short-term care. I didn't dare tell her that we'd missed him horribly and felt guilty about it, so I made out we had a great time.'

> 'We sat and stared at each other all the evening when he went to the hostel. All the time I felt that I wanted to rush up there and fetch him back, but I didn't tell the social worker that, as she'd said we'd got to enjoy ourselves when he wasn't at home.'

Parents' feelings about separation are also being denied by professionals who try to use short-term care to enforce advice which is contrary to family wishes. The parents of a 15 year old boy called Peter only wanted short-term care every Tuesday night, but the social worker began to press them to let him have two weeks in and two weeks out because she thought the boy was causing more stress in the family than the parents would 'admit' and his sleeping habits needed 'correcting'. One of the family habits which worried the social worker and the teachers was that Peter slept in his parents' bedroom. No matter how far the social worker was right in her interpretation of the family's needs or how far influenced by her own feelings of horror at the thought of having to care for such a difficult boy, the fact remained that in not recognising the love those parents felt for their son, she also failed to recognise that the pressure she began to put on them was itself causing stress. The parents felt that they were under threat to increase their separation periods and were being criticised for their style of care which they had devised and used quite contentedly for a number of years; they also felt their son was being threatened by professionals suggesting that he should have more residential care and have his behaviour changed. The family's life-style might have seemed rather unusual by majority standards, but the parents found it worked in caring for their very handicapped son and had not asked for advice in changing it.

The above story raises many questions. Should professionals try to change the life-style of a family without the parents themselves asking for advice? Should short-term residential care aim to do nothing more than offer support in a way that makes as little disruption as possible to the life of the family (taking into account the normal worries of parents about the separation), or should it *also* include advice which may disrupt family life but perhaps ultimately benefit the child and his parents? Few units were tackling these questions, the staff seeming to be confused about how the role of residential care may also dovetail into using professional expertise in such matters as behaviour changing, physiotherapy and teaching the child skills which his parents may find it difficult to teach.

Publicity about the setting up of a service and its financing, references to it in local papers and at parent group meetings, can increase the pressure on parents to use it. The social services department in one area admitted pressuring parents to use a new short-stay hostel in order to keep the beds full and thus justify the high cost of opening it. Reports to local planning committees may refer in disappointing tones to the under-use of a short-term care facility and this may result in parents being encouraged to increase their use, but it could be more revealing to examine whether the service which has been provided is really what the parents want. Perhaps a reliable sitting-in service in their own home might have been more popular, or more day-care in after-school hours or more home helps going in at particular times of the day? Are parents being asked what forms of support they would like? A common fault in planning residential short-term care is that a hostel or an ungraded ward is presented as the *only* available form of help and the professionals expect every family to be suited by it, whereas something less costly and more appropriate might be provided.

In one area the parents of very young mentally handicapped children (six and seven year olds and the under-fives) tried to resist using the local short-term hostel because they did not feel they could justify putting their young children into any form of residential care, especially as they were not having any major problems with them. But they were told by the social worker that 'Even if you have no problems *now* it would be wise to get your children used to being away from home in preparation for the time when you *do* have problems, and anyway it is good for them to go away when young as they'll be used to it by the time they are older and do have to leave home'. This might be wise advice for parents in their late 50s or early 60s who have adolescent sons and daughters who might benefit from an experience of living away from home, but for young parents of young children, it is very unnecessary pressure and not in keeping with normal principles of child care which favour keeping young children within their own families.

> Mrs Roberts, mother of eight year old Kathy said: 'It is made so easy for us to put our children into residential care. In fact, I feel that if I don't do so, and if I say I can manage, then I will be labelled odd by *other parents* as well as by the social workers'.

The eager way in which professionals encourage the use of short-term care services was referred to by Mrs Hamish, the mother of three year old Flora:

> 'I hope the parents don't use the short-term care ward too much; but they *will* because the doctors and social workers make it very easy

> for us to let our children go. We are *encouraged* to send them away. There is danger in taking young children away from their families too much, but doctors don't seem to see this, nor social workers.'

Professionals' assumptions that parents of handicapped children are eager to use residential services, eager to leave their children with strangers, suggests that professionals are over-confident about the services they are offering and ill-informed about parents' feelings of affection for their handicapped children. One consultant psychiatrist went into a mental handicap hospital ward and saw a mother who had just brought her seven year old child in for short-term care and he said: 'Well, this is the right place for her isn't it?'. The mother's later words were 'How could he say that? How could he go into that ward and not see that it was unsuitable for any child?'.

When there is a strong encouragement to use short-term care services and a denial of normal worries about separation, the parents may be reluctant to admit their own misgivings about the service and the disturbance that the experience seems to be causing their children. The parents in the study often felt that their children were 'different' when they returned home, but they did not discuss this with the care staff or social workers who had persuaded them to use the service in case it seemed as if they were complaining. (Regarding the effects on children, see Chapter 6.)

Some parents did not see any professionals following their first experience of putting their children into short-term care, and they did not like to telephone the units to ask how they had got on or say that they seemed disturbed by having been away. If there is little or no contact with care staff after the children return home it means that the parents know nothing about what it was like for the child and what he might have done during the time away; the whole experience, although carefully described as 'shared care' by the professionals who organise it is, in reality, a blank in the relationship between parents and children. (See Chapter 5 for special reference to parent/staff contact.)

Parents may be loath to bring up problems of short-term care at meetings of local parent groups for fear of offending staff who may be present or of getting disapproving reactions from other parents. Those who had tried to promote critical discussion at parent meetings, said there was a rapid 'closing of ranks' by the staff who were present and the more dominant parents who had been active in campaigning for short-term care and firmly believed that the facility was excellent.

If parent groups are convinced that short-term residential care is always good, their critical perceptions of a facility are likely to be blunted and justified criticisms are not listened to. One parent who had a genuine complaint about a hostel became very unpopular with other parents when she continuously referred to her child coming back dirty and bruised; the other parents disapproved of her criticisms and it was some time before they were persuaded that there was genuine reason to be concerned about the quality of care in that particular hostel.

Individual parents who try to resist using residential care because they have a normal wish to keep their child at home because they love him and enjoy him as much as their other children, and who are worried about the separation and how it will affect their child, find it difficult to cope with the combined pressure of parents and professionals who believe that short-term care is always right for everyone. In one area there was a new local authority hostel and a very active group of local parents who, like the professionals, were keen to see it fully used. They did not allow criticisms of it and parents who said they did not want short-term care were sometimes told that they were:

'over-protective'

'needing the child more than the child needs you'

'not looking realistically to the future and preparing him for the time when you are no longer there to look after him'

'denying your child opportunities for maturing or making friends or becoming independent'

'thinking you know best and that nobody else can look after him properly'

'denying your other children a normal life at weekends'

'putting your marriage at risk'

'putting on your married children to look after him'

'damaging your health by not getting a break and therefore harming him in the long run'

'disloyal not to use the hostel when we parents have fought for so many years to get the facility'

Of course, any of the above suggestions may have contained a grain of truth, but the sentiments they expressed came dangerously near to stereotyping handicapped children and dismissing the existence of any normal affectionate relationships between parents and their handicapped children.

Professionals sometimes make sinister interpretations about parents who have a normal wish to keep their handicapped child at home simply because he is no more trouble than their other children. 'The parents are using the child as an excuse not to do things and lead an ordinary social life' was said by a social worker about parents aged in their 30s who had a ten year old child and a six year old very able child with Down's syndrome who joined in the many activities enjoyed by the family. 'They are hiding the child away unfairly' was said by a teacher about the parents of a five year old child who were refusing to send him into short-term care. This latter statement, implying that keeping a child in the family is 'hiding him away', but sending him into residential care is somehow putting him into the community, suggests that the teacher herself had a very curious perception of community care.

The reactions of siblings to short-term care

One of the most consistent arguments in favour of short-term care is that it benefits the siblings: making it possible for them to enjoy outings with their parents which they may not have when the handicapped child is at home, giving them restful nights, providing them with a quiet period for study, enabling them to get more attention from their parents, making it possible for them to invite friends home.

One hundred and seven of the 123 families in the study had one or more other children in addition to the handicapped child. The ages of the siblings ranged from a few months to the early 30s. In five of the families the handicapped child was the only one still living at home, but the adult siblings kept in regular contact with the parents.

In an effort to discover how siblings might be affected by the use of short-term care, the parents were asked, 'What do your other children think about the handicapped child having short-term care?'. Ninety-five of the 107 parents answered the question, 32 by post and the other 63 during their informal interviews. Siblings were present during 34 interviews, and although the question was not put directly to them, none disagreed openly with their parents' answers, and those who were old enough to do so volunteered their own opinions about short-term care services.

The answers given by the families suggest that it should never be assumed that short-term care always benefits the siblings. It may, indeed, cause them uneasiness or disturbance, and even those who feel the benefit of the rest and quiet afforded by the absence of the handicapped child may still miss him badly and look forward to his return. Sibling anxieties about short-term care sometimes resulted in changes in their behaviour when the handicapped child was away, such as disturbed nights, wanting to sleep with the parents, unusual quietness, obvious loneliness and the inability to play contentedly, and anxious questioning about the whereabouts of the absent child. Forty-seven of the families reported the siblings as having anxieties or other negative feelings about short-term care being used, 47 reported them as accepting it or being pleased about it; one parent said that she could not say what her daughter felt about the brother having short-term care. Table 4 shows the parents' answers.

It was surprising to find that 15 of the 17 families who had a child with Down's syndrome (considered fairly easy to manage) were in the group of 47 describing siblings as being pleased or accepting the need for short-term care, whilst in the total of 22 families who had children who are usually considered more difficult to care for, because they either have behaviour disorders or are totally physically incapacitated, there were only six siblings who felt pleased and as many as 16 who felt anxious about the handicapped child going away. The answers appear to cast doubts on the popular theory that short-term care is always a major source of relief to siblings when there is a very dependent and difficult child in the family.

The answers might suggest that children with Down's syndrome are unacceptable to their siblings, but a more likely explanation is that the most severely handicapped children are greatly missed by their siblings because they need a lot of care and attention and they have a lot of influence on the family life-style; the siblings will be very aware of their presence and some are likely to be involved in their care so they are bound to miss them and suffer some anxieties on their behalf when they go away. The greater the family's involvement in the care of their handicapped child, then the greater their sense of loss when he goes away. For example:

> Mr and Mrs Field had a 14 year old handicapped daughter, Tess, who needed everything done for her and took a great deal of care and attention. Her 11 year old brother, George, was always very anxious when she had short-term care in the mental handicap hospital. 'George does not understand that mum needs a break and he badly misses Tess. He always buys her a present when she is away to have as a surprise when she comes back, and he visits her up there anyway every time she goes', said Mr Field.
>
> Mr and Mrs Smith had a totally dependent daughter, Nancy, aged five, two older daughters aged eight and nine and a younger one aged two. The older sisters were described as missing the handicapped child 'very much indeed'. She was much loved in her family and

Table 4 Reactions of siblings to handicapped children having short-term care

	The children's handicaps					
Reactions of siblings (94 families gave opinions)*	Down's syndrome (17)	General mental handicap† (55)	Behaviour problems (12)	Very physically dependent (10)	Only 1 other sibling in family	Single parent families
Not bothered, quite accepting absence of handicapped child (24)	11	11	1	1	10	—
Pleased about the absence of handicapped child (23)	4	15	2	2	8	3
Total expressing positive feelings about short-term care (47)	15	26	3	3	18	3
Felt relief but missed the handicapped child (21)	—	15	6	—	11	4
Missed the handicapped child and made uneasy by his absence (16)	1	8	2	5	10	1
Jealous about child going away (5)	1	3	—	1	2	1
The use of short-term care a cause of dissension (3)	—	2	—	1	3	2
Siblings critical of care given in the facility (2)	—	1	1	—	1	—
Total expressing negative feelings about short-term care (47)	2	29	9	7	27	8

* Ninety-five answered the question and of these 94 gave opinions and one mother said she was unable to say what the sibling thought about it.

† The term 'general mental handicap' is used to describe the group of children whose mental handicaps ranged from very severe to severe, but they did not present problems of physical incapacity or behaviour disorders.

> whenever she was present during my visits she had plenty of cuddles and petting from the sisters and I would be invited to have her on my lap and 'take a turn at cuddling her'. The family was suffering from poverty due to the father's long-standing unemployment and they lived bleakly in a cramped council house in a very poor area. The mother had chronic bronchitis, which added to their difficulties. But in spite of their problems the family was close-knit and stable. The handicapped child, usually lying on a settee in the centre of the living room, was understandably missed by her sisters whenever she was sent away. When the day came round for her return the sisters would keep asking eagerly, 'What *time* will she come?', and would spend hours looking out of the upstairs windows waiting for the car to arrive. The parents had stoutly resisted long-term care in the local mental handicap hospital, which had been recommended by professionals who were worried about the family's social problems. They were using short-term 'fostering' and the siblings had visited the foster family and been given careful explanations about Nancy's absence and the need for her to sometimes go away. The foster home was seen as an extended family and the foster parents spoken of as 'aunty and uncle'. But in spite of the positive feelings that the siblings had about the foster parents, they still missed the presence of their helpless little sister.

> 'Jenny messes up Mary's things and sometimes stops her playing or having her friends in, but she still misses her when she goes in the short-term care place. She keeps asking 'when she is coming home again' said Mrs Baker, the mother of five year old Jenny who was very disturbed and over-active, and eight year old Mary.

The extent to which the sibling missed or did not miss the handicapped child, and how much they were upset by the use of short-term care, seemed to be influenced not only by the handicaps of the children but also by their ages and position in the family. When all the children were in infancy or when there were younger siblings the handicapped child was missed as a companion irrespective of the severity of the handicap:

> 'Don't let him go. Can't we get him back?' was the reaction of a four year old sister about the short-term care of her totally dependent brother aged eight. Her mother said that she missed him as a companion and somebody to play with and cuddle.

Some siblings accepted the absence of the handicapped child for one or two days and would then begin to get anxious.

> 'Joyce's little brother just asks where she is going and I explain that she is going into the unit so we can have a rest, but after a couple of days he starts missing her.' (A mother describing the reaction of her two year old son to the absence of his four year old sister who had a severe behaviour disorder.)

> 'His eight year old brother misses him as they share a room. He says "I do miss him, when are you going to fetch him home again?"' (A single parent with two sons aged ten and eight years old, the ten year old severely mentally handicapped.)

> 'Rachel misses Thomas. She is always asking for him when he is not here. She says "Where's Tar-tar?" (Rachel repeated this to herself several times after she heard her mother telling me this during my visit). She loves him and misses him always. When she was a baby and Thomas was only two he used to climb dangerously over her pram and get into it on top of her. I got worried in case he suffocated her, that is why we started having short-term care. But Rachel can stick up for herself now.' (The mother of a two year old daughter and a four year old mentally handicapped son.)

The picture given by this young mother was one of happy companionship between her two small children and a normal missing of each other when they were parted.

Irrespective of whether a child is handicapped or not, it is common for parents to worry about a new baby's safety when there is a toddler in the family, but the worries diminish as the baby gets older and less vulnerable. Perhaps the young mother mentioned above and her health visitor and social workers over-reacted to the fact that the two year old was mentally handicapped when he 'climbed dangerously' into the pram of the new baby. When Rachel was a tiny baby and Thomas an active handicapped two year old, the mother did need some help, but a sitter or link family would have been more appropriate than the hostel care that the little boy was given. After Thomas started school and the young sister became able to 'stick up for herself' and there was a growing companionship between them, it was questionable whether short-term care in a hostel was still necessary. It is all too easy for arrangements to continue long after the situation which precipitated the initial decision has changed. Frequent careful reviews should be made of families' changing circumstances, with a view to tailing-off the short-term care when it is no longer really necessary, or making a different arrangement to help the family.

In looking at sibling reactions to short-term care, there also seemed to be some relationship between the extent to which a handicapped child was missed and whether there was only one other sibling in the family. A higher proportion of negative feelings about short-term care was reported when there was only one sibling (see Table 4). Again, this would suggest that the companionship of the handicapped child and acceptance in his family may be underestimated by professionals who recommend that short-term care will always benefit the siblings. The absence of a child, no matter how handicapped, from the family can mean loss of companionship but can also cause feelings of insecurity for the sibling who is left behind on his own.

Short-term care appeared to be most welcome to siblings when all the children were in adolescence and fairly near in age. This might indicate that handicapped siblings become less easy to accept as they get older, when the abler children forge ahead intellectually and the simpler interests of the handicapped sibling perhaps become less tolerable. However, it might also be explained by the normal turmoils of adolescence aggravating difficulties and intolerance – sibling pleasure at the use of short-term care then being more related to the normal irritable reactions of adolescents unable to get on with each other than to the handicap.

> Fourteen year old Kevin was quite independent, although severely mentally handicapped. He could find his own way to his special school nearby, and was able to cycle on his own in the quiet road where he lived. He had short-term care regularly at the local health authority unit. 'Marvellous peace when he is away', said his 13 year old sister. The parents said he was no trouble and his handicap caused them few worries, but it was 'certainly more peaceful' in the house when he was away, as it put a stop to the bickering between brother and sister.

'Marvellous peace' was a very normal remark for any adolescent sister to make about the absence of an adolescent brother. Was it possible that the brother's handicap was being blamed for arguments in the family which are very common when there are adolescents at home, whether they are handicapped or not? Although it would not do to underestimate the problems that might arise in families where there is a handicapped adolescent, they should be kept in perspective, and professionals who are organising short-term care services might ask themselves whether it is wise or fair to remove the handicapped youngster to a residential setting for short periods in order to alleviate family tensions which are normal and common.

The family interviews indicated that sibling tolerance of each other when they were near in age was high in infancy, became low in adolescence but increased again as siblings reached adulthood, a common feature of family life. And when there was a big gap in ages, with the handicapped child the youngest in the family and the next sibling as many as nine or ten years older, they often had a good affectionate relationship and were very tolerant of each other; the older siblings being protective towards the handicapped child and worried about how he or she would be looked after in short-term care, although at the same time they agreed that there was a need for their parents to have a rest. Some of the answers suggested that it was not only the younger siblings of the handicapped child who missed him or were disturbed by his admission to short-term care, but adult siblings still living at home were also made anxious by his absence. For example:

> 'Too quiet when she's away . . . miss her although she's a pest, it is not normal without her at home.' (Said by two brothers, both in their early 20s and still living at home, about their 16 year old mentally handicapped sister.)
>
> 'We do not like her going away, we are fond of her and used to her being at home with us.' (Said about a 13 year old mentally handicapped sister by her two brothers and two sisters, all in their 20s and still living at home.)

Older siblings, some of whom were in their late 20s and 30s and had left home and had their own families, were generally very concerned about their ageing parents left caring for a handicapped child and they were relieved at the idea of short-term care.

> 'They think short-term care is very good because it gives us a break.' (Parents in their mid-50s with a ten year old handicapped boy and three sons and a daughter, all in their late 20s, married and gone from home.)
>
> 'My daughter agrees that we need a break from Terry, as no matter how we try life tends to revolve around him and we cannot help neglecting ourselves.' (Parents in their late 50s with a nine year old son with Down's syndrome and a daughter aged 23 who was no longer living at home.)

The understanding shown by the siblings in the last two families was more common than the reactions of a son and a daughter, both in their 30s and still living at home, who became angry with their 56 year old widowed mother for using short-term care for the 16 year old, totally dependent son. Their anger towards their mother for wanting the handicapped son to go away from home suggests that what families think of services may sometimes be as much related to family life styles as to the fact that a child has a handicap.

There were older siblings who understood that short-term care was not only helpful for their ageing parents, but also for the independence of the handicapped children – a preparation for their growing up:

> 'Our other children are grown up themselves and realise that the handicapped boy has to have a chance to widen his horizons as they did.' (Parents in their late 50s with a 12 year old boy with Down's syndrome and a son and daughter in their 20s who had both left home.)

Older siblings may also feel glad about short-term care because it not only gives their parents some relief and is an opportunity to prepare the handicapped child for independence, but it also opens up other avenues of care for him which may absolve them from having to take full responsibility in the event of their parents' death.

Although most older siblings appreciated the necessity for parents to have a break, they sometimes wished that there was a different means of organising it and were very critical of their local services. Following are two accounts of worried older siblings met during the study.

> The 19 year old brother of a 14 year old very severely handicapped boy visited him when he was having short-term care and said that he was 'disgusted and angry' to find that when his parents had gone away on holiday, trusting that their son would be well looked after, he was in fact quite neglected. On one occasion when the brother visited, he had to draw the staff's attention to the handicapped boy getting out of the gate unobserved. And on another visit he saw him 'roaming about eating rubbish, whilst, nearby, another helpless handicapped child was having sand poured on his face – and children were left for long periods completely ignored in corners'. The brother said he was placed in a complicated and distressing situation when noticing this poor care as he felt responsible for his parents' need to have a peaceful holiday but at the same time very worried about his vulnerable brother. He was unable to get advice from anyone, as he was not in contact with a social worker and felt that he did not know the staff well enough to discuss the problems with them.

> A girl of 19 described how she went with her mother to visit her 12 year old handicapped sister who was receiving short-term care in a mental handicap hospital ward. They arrived unexpectedly and were told by a male nurse that they should have telephoned before coming. They found the handicapped child in a dirty condition,

> lying on a battered sofa in an unpleasant smelling room which had high windows. The staff seemed 'very unfriendly'. The daughter said, 'Mum and I broke our hearts when we saw her'.

The type of short-term care described in the above two stories places extra burdens on older siblings, making them feel not only responsible for the handicapped child and fretful for their parents' worries but depressed about the future and wondering whether there will ever be reliable services to care for the handicapped sibling or whether they themselves will have to take on full responsibilities when their parents die.

Professionals sometimes refer to short-term care being of particular benefit to siblings in single parent families but, out of the eleven single parent families where there were more than one child, eight reported that the siblings were not entirely happy about the use of short-term care.

> Mrs Gittings was a widow with three children: 15 year old Grace, ten year old Mark and seven year old Ian. Mark was mentally handicapped and had a four week period of short-term care every third month throughout the year. Mrs Gittings said that her other children were 'Never happy about short-term care. Grace really resents him going away and gets quite upset about it, and Ian misses him badly and keeps asking me about when he is coming back. He shares a room with him so I suppose he misses him the most'.

The uncertainty felt about short-term care by siblings in single parent families probably indicates their feelings of insecurity caused by the loss of a parent (whether through separation, divorce or death). Short-term care, instead of being a welcome relief and enabling them to get more attention from their remaining parent, may seem quite threatening and bring back painful memories of having already lost one member of the family. For this reason it would seem wrong for professionals to assume that short-term care will always benefit siblings in single parent families.

How siblings come to terms with short-term care

Twenty-one of the families mentioned that the siblings missed the handicapped child but accepted that short-term care was necessary for the sake of the rest of the family. Siblings use a variety of arguments to reconcile themselves to the alien arrangement that one member of the family gets intermittently looked after by other people; such as, there is a need for the parents to have a rest, mother is ill, the handicapped child's routine gets upset if he goes on holiday with his family. The reasons often reflect the parents' own ambivalence about short-term care.

> 'They understand that Mavis went into short-term care when I was ill and couldn't cope with her after my operation, but they would not like it if they thought we were sending her away because we just needed a break from her.' (Mother of a five year old handicapped daughter and two sons aged ten and nine.)

> 'They get a bit upset at her going. They said they wished we could take her on holiday. There is a lot of conflict about it really, but they realise that she gets upset at any changes in her routine and that this could disturb their holiday.' (Mother of a five year old handicapped daughter, a son aged ten and a teenage daughter.)

> 'If it is not possible for us to have a properly enjoyable holiday *with* Sarah then short-term care's the best thing, but only for a short time.' (Said by brothers aged 11 and 15 about their 13 year old handicapped sister).

In some families the siblings had been carefully introduced to the short-term care facility, therefore they did not feel that there was a complete blank between them and the place where the handicapped child was staying. If the child was being fostered, the siblings were taken to meet the foster family or, if a local authority hostel or hospital unit was being used, an opportunity was found for them to see where their brother or sister would sleep and play.

> 'She's quite relieved that she's got us to herself for a while. It is not fair on her never to have a break from her little sister, she needs such a lot of care. The hostel gives *us* a break *and* her. But she likes going there herself, too, to visit and play with their toys and see where her sister will be sleeping, so we do not think she sees it entirely as sending the handicapped child away because we don't want her.' (Parents of daughters aged seven and three years old, the younger one handicapped).

In the grounds of one health authority unit there was an adventure playground and the siblings enjoyed using it when they went to visit, collect or leave their brothers and sisters. However, some units were never seen by siblings, and even the parents themselves had minimal contact because the staff did not encourage family involvement or because the unit was too far from the family home to allow easy contact; where the handicapped children went and what happened to them must have been quite a mystery to their siblings.

How siblings perceive short-term care and the handicapped child

Because short-term care is a peculiar form of intermittent removal and return of a child in and out of the family circle, it may understandably have an unsettling effect, and even be quite frightening for young siblings. Do they fantasise about the handicapped child's absence, especially if it follows an episode of difficult behaviour? Do they think that short-term care is a treat to be envied or a punishment to be feared? If, as sometimes happens, it is used as a threat to the handicapped child and is connected with his parents' anger with him, the siblings may feel very uneasy and wonder if they will be the next ones sent away, especially if they do something disagreeable.

In their efforts to put short-term care across to the handicapped children as a good idea, some parents talk about it as a 'holiday' and emphasise how nice it will be; siblings may then start feeling jealous and think that they are missing something rather special.

> 'Phyllis is only little and she gets very jealous of him and says, "Why can't I go and stay somewhere nice too?"' said the mother of five year old Phyllis and Keith who was aged seven and mentally handicapped. Phyllis' parents sometimes arranged for her to stay with the grandparents while Keith was away in the hope that this would stop her missing him so much and feeling so jealous, because she could then feel that she too was getting a nice 'holiday'.

Nobody can be certain how the siblings perceive the comings and goings caused by short-term care, or how much it may actually alter their image of the handicapped child. Is the child recognised as being *handicapped* for the first time when seen in short-term care amongst a crowd of other children who are all handicapped?

> 'Her brother does not like going to the hostel when she is having short-term care. He got frightened by an over-active child once, who bashed into him. He misses her and asks when she is coming home again. He always goes into her bedroom in the mornings to play with her.' (Parents of a three year old, totally dependent handicapped daughter and a six year old son).

This brother could happily accept his own very handicapped sister, but he was upset by the congregation of many handicapped children altogether in the hostel. Seeing a lot of handicapped children together, he felt afraid; such distressing sights were not part of the close and loving relationship he had with his sister, whose familiar form was comfortable and companionable to him regardless of her severe physical incapacity. Was his image of his sister substantially altered when he saw her at the short-term care unit? Perhaps he would have felt more secure about her if she had stayed with a 'foster' family instead of in the crowded hostel.

In their efforts to explain short-term care to siblings, some parents and professionals accentuate the advantages that will accrue from the absence of the handicapped child, and this may affect the siblings' image of their handicapped brother or sister and create prejudice and resentment when none existed previously. For example, the parents may say that when the handicapped child is at home:

> 'We cannot enjoy things together.'
>
> 'I (mother/father) cannot give you proper attention.'
>
> 'You cannot bring your friends home when he/she is here.'
>
> 'We cannot go to the swimming pool/football match/museum/zoo/ or walks on the moors, because he/she gets upset, or the wheelchair won't fit in the car.'

But when he goes away:

> 'We can go on holiday together and have a nice time.'
>
> 'We can get more rest and peaceful nights and then we are not so irritable with each other.'
>
> 'We can have friends in, and parties.'
>
> 'We can have a meal in peace.'
>
> 'We can go to exhibitions/films/football matches/museums.'

Professionals and parents are likely to promote a very negative image of children who have handicaps if they constantly emphasise the negative aspects of a handicapped child in the family and list the advantages of his going away.

But does a physically immobile handicapped child of four years old really create more problems in his family than an ordinary demanding active four year old? And does an adolescent with Down's syndrome create more worries than the normally rebellious adolescent who is studying for O levels, agitating for a motor-bike, seeking sexual freedom, staying out late? The worries may be very different (and long-standing) with a handicapped child, but at the same time it would seem very important that the negative effects of the handicapped child on family life are kept in proportion and occasionally reviewed to see if the problems they present are grossly in excess of those presented by children who are not handicapped. When making decisions about short-term care, questions such as the following might well be asked: would a normal two year old be sent away for short-term care because he was exhausting his mother by his endless repetitive questions and demands, and, if not, then why send away a handicapped two year old who may never speak or get into the cupboards and take out the saucepans, but who needs help with his feeding difficulties? Do adolescents who are not handicapped get sent to hostels for short-term care because they are infuriating, rebellious and a nuisance at home, and, if not, then why is it thought necessary to send away an adolescent with Down's syndrome who may, in fact, be less of a nuisance than the normal adolescent? If the burden-and-bother aspects of handicapped children are always highlighted, this may lead to decisions being taken about them which are not only unwise, but also unjust. (See also pages 68–69 and 135–137.)

One of the dangers of having to make decisions about handicapped children which do not arise for those without handicaps, is that satisfactory reasons have to be found to justify the use of short-term residential care and those reasons are likely to stereotype the handicapped children and prejudice their siblings against them. The attitudes of the siblings may change towards the handicapped child once he starts having short-term care and the parents explain his absence by saying how much better it is without him and what a nuisance he has been at home. Sibling tolerance of the handicapped brother or sister may then lessen. In fact, short-term care may be the start of a growing separation between the siblings and the handicapped child – not for the right reasons such as the child's need to become gradually more independent, but because the family have begun to develop a negative image of him.

> 'She likes it when he goes away. I can do things with her. The first few times he went in she got a bit upset, but now she does not mind. She appreciates the quiet. Resentful more of him now and not very pleased to see him back again.' (A mother, describing the reactions of a ten year old sister of a seven year old handicapped brother, a year after he started having regular periods of short-term care.)

Was the sister's resentment new, caused by the parents' explanations that short-term care was necessary because he was such a nuisance, or had it always been there but was only now finding expression as the parents themselves were openly voicing negative attitudes towards him as they tried to explain and justify their use of short-term care?

Does short-term care expose latent feelings of resentment towards the handicapped member of the family?

> 'They look forward to it, as they can go out and have more attention from us. They lock their doors against her now when she is at home.' (Parents of a seven year old girl with Down's syndrome and a son and a daughter aged eleven and nine.)

This child was having extensive short-term care (one long week-end or one whole week, every month throughout the year). The parents found her difficult to accept and they voiced their shame about her: '. . . people laugh at her in the streets and shops'. The mother said that she had wanted to get the little girl put away somewhere permanently ever since she had been born. If she had been born a decade earlier when it was more common to get a handicapped child put away permanently into a long-stay hospital, this is doubtless what would have happened to her. But in the late 1970s, in that particular district, regular short-term care had replaced long-term hospital care. The child was considered very acceptable in the short-term care hostel and at her special school, because she was more capable than most of the other children in her group and making good progress.

> 'His brothers are very happy about him going away as he messes up their games. He broke their models so they are glad to see him go. They will reject him later if they are sickened of him in childhood, and we don't want that.' (Mother of a six year old boy with Down's syndrome and sons aged eight and nine.)

This mother was the wife of an officer in HM Forces and she felt some difficulty in accepting her son's handicap, especially on social occasions connected with her husband's colleagues and the service ceremonies which the family were expected to attend. She said that short-term care was 'helping his brothers to develop more positive attitudes, so that in later life they will be more likely to keep in contact with him'. However, it was possible that some of the explanations given about the advantages of short-term care were reinforcing the brothers' negative attitudes: 'We can go out to nice things when he goes away' and 'He will not break your things' and 'We can go to Daddy's parades'.

> 'They don't like him so they are glad; glad when he is not here. They say "Urgh, *he'll* be back tomorrow".' (Father of a three year old, totally dependent boy with a twin brother and an eight year old brother.)

The reaction of the last family to one of its members being handicapped was in complete contrast to the Smith family referred to on pages 65 and 67, where there was a similarly handicapped child, also aged three, and almost identical social circumstances—poor council housing, unemployment—but a marked difference in attitudes to handicapped children, suggesting that the problems of caring for these two very dependent children was related more to differences in family attitudes to handicap than to the difficulties presented by the two children and the accompanying social circumstances. Such differences in family attitudes were found throughout the study and might explain in some measure the way that short-term care is used, *or not used*, by families. Blanket assumptions should never be made about the problems caused to ordinary children by having a handicapped brother or sister, nor about any family's needs for short-term care and their use of it. And it should always be borne in mind that short-term care may influence the siblings' image of the handicapped child.

Grandparents and short-term care

From information given in the interviews and from the records of the children using the units which were visited in the study, there appeared to be some connection between the use made of short-term care and the degree of parent/grandparent contact.

Out of a total of 200 families who were using Rivermead local authority hostel, there were only 34 known to have *helpful contact* with grandparents. Contact was considered 'helpful' if the grandparents were assisting with the children's care and giving consistent moral and physical support on a regular basis; for example, babysitting, having the children to stay with them for days or nights, doing occasional shopping, laundry or sewing for the family, taking the children on outings. Families which had these helpful contacts with grandparents seemed to be making fewer demands on short-term care facilities.

The high number of Rivermead families who did not have helpful contact with grandparents might have been partly explained by career mobility; Rivermead was sited in a pleasant university town, with light industries, within easy commuting distance of London and popular with young professionals who wanted careers in technology, science, education and commerce and were willing to move away from their childhood home areas. Mobility causing loss of extended family support was obvious in most of the areas visited during the study. Not only were young parents moving about because of employment and career prospects, there was also rehousing in 'new towns' and grandparents retiring to country or coastal areas.

The four main reasons for lack of helpful contact between families and grandparents were:

1 When the children's parents were from another country; some of the parents in the study had come from Spain, Greece, West Indies, Hong Kong, Ireland, Germany, India and Pakistan, and their own parents had remained in the country of origin.

2 When the father was in HM Forces; this meant the family moved around and it was easy to lose contact with the child's grandparents. One of the short-term care units visited in the study was sited in a naval area and was used by a group of young parents whose contact with their own parents was minimal because the naval base was a long distance from their original family homes.

3 When the grandparents were early middle-aged; they were then likely to be working full-time or even have young children of their own to look after and be too busy to give regular help with a handicapped grandchild.

4 When the parents of the handicapped children were in late middle-age; it was then likely that their own parents were dead or frail and dependent and in no position to help. Indeed, elderly grandparents often needed support themselves, which made life even more complicated for the parents of the handicapped child. One reason why some of the children in the study were having short-term care at weekends was so that their parents could travel long distances to visit their own parents who were frail, elderly and widowed and needed regular support and care. Sometimes these elderly widowed grandparents were alone in the seaside resorts to which they had retired a few years earlier.

The problem facing the Osborne family was a common one for parents aged in their late 40s. Mr Osborne's parents lived 200 miles away. Mrs Osborne's mother was a frail widow aged 88 living twenty miles away. She was visited every week by Mrs Osborne (who had to do the journey on very inadequate public transport) and given help with her washing, cleaning and cooking. Mr Osborne stayed at home to look after the rest of the family. Their 13 year old, multiply handicapped son was one of six children aged between five and 15 and he was receiving short-term care as often as 1–2 nights each week throughout the year. The unit was within walking distance of home. Mrs Osborne said, 'We've got nobody in the *family* to help us now, so we have to think of the unit as uncle, aunty, grandparents, rolled into one. And if it weren't for the unit I'd never be able to help my Mum as I do now'.

A good locally based short-term care unit can play an important role in replacing the help which was once given by grandparents. Some grandparents had been regularly helping when a handicapped child was a baby or in childhood, but found it increasingly difficult to cope with a handicapped adolescent who was very lively or physically dependent. The parents would be reluctant to ask their ageing parents to help when it could mean lifting a heavy cerebral palsied adolescent, and the grandparents had little confidence in their ability to cope with any problems that could arise if they were baby-sitting, as they were afraid they might fall themselves or lose control of the situation.

> 'My mother tries to help but she cannot lift Lilian much now. She cannot look after her for a night while we go out, not like she used to. She would be too much for her. Lilian is a real handful, she is on the go all the time. My mother just helps a bit with the ironing and looking after her for a few minutes while I go out to the shop on the corner.' (Mother of a nine year old, blind, multiply handicapped child who liked crawling energetically around the house.'

Some grandparents, however, were taking a very active part in caring for a handicapped grandchild single-handed, although they were getting elderly and had other problems to contend with; for example:

> Seventeen year old Christine was very severely handicapped, unable to speak or use her hands and had certain allergies which occasionally caused medical problems. She had been living with her maternal grandparents for ten years, since her mother had emigrated to Australia after her marriage had broken up. The grandfather had died a year before I met the grandmother. She was in her mid 60s. Understandably, the difficulties of caring for Christine had been increased since his death and the grandmother was suffering from bereavement and exhaustion. In addition to caring for Christine, she also had her own elderly mother (aged in the late 80s) living with her and needing a lot of looking after. After the grandfather died, Christine began to have occasional weeks of short-term care in the mental handicap hospital, but the grandmother said they missed each other although the short-term care breaks were helpful.

> Twelve year old Doreen had been living with her maternal grandparents for eight years, since she had been received into care at the age of four after her mother committed suicide. She was fairly able girl who could walk and talk and feed and dress herself, but

> sometimes she 'behaved oddly' at home and got very upset at any changes in her routine. Her grandmother was 65 years old and her grandfather was in his mid 70s and suffering from chronic bronchitis. Doreen had one long weekend in a short-term care hostel every month.

Professionals sometimes disapproved of extensive support given by grandparents.

> The parents of nine year old Michelle were well supported by both grandmothers who were in their early 50s and lived nearby and willingly looked after Michelle in the evenings and weekends to enable the parents and older child to go out. Michelle did not go to the local short-term care hostel because her parents felt that there was plenty of help available from the grandparents. However, social workers and doctors believed that this help was likely to 'restrict the parents' ability to give up the handicapped child to full-time care in later years'. In the following correspondence the professionals voiced their disquiet about the grandmothers' help: 'Terrible problems are created when we have mothers who are so well supported by grandparents. They just go on coping and fail to realise how extensively their lives are becoming entirely related to the handicapped child . . . when it becomes important for the child to separate it is exceedingly difficult for the mother'.

In another district, the professionals interpreted extensive help given by maternal grandparents as 'a failing on the part of the mother to develop full responsibility for her handicapped child', and they suspected the grandparents of 'trying to retain power over their daughter by making themselves indispensable'.

Whatever interpretations may be put on grandparents' support, the fact remains that it is a highly appreciated source of physical and moral help, and can prevent or delay the child's admission to long-term residential care. Whilst it may be important to respect the views of professionals who are skilled in analytical casework, it would also seem important for family relationships to be respected and nurtured. It is significant that close and loving relationships between grandparents, their children and grandchildren are usually thought delightful and positive and it is only when one of the grandchildren is handicapped that tones of suspicion and censorship creep in. Such criticism of inter-family relationships when there is a handicapped child suggests that some professionals have a very negative image of mentally handicapped children and their place in the family.

In some instances the grandparents were living very near but they did not feel able to help because they did not understand their grandchild's handicaps. They were perhaps fearful of the children if they were active or likely to have fits, or they were upset by their multiple physical disabilities. Some were described by their sons and daughters as 'being very upset and crying whenever they see our child'. In their distress they seemed to want to deny the handicap and they would irritate the parents by their insistence that the doctors were wrong and that the grandchild was normal and would soon start making progress.

Some grandparents were inclined to interfere with the parents' handling of the child. In-law interference in child upbringing is of course common, but it is perhaps even more difficult to cope with if the children are handicapped. It may cause considerable problems when the parents are following their child's physiotherapy programme or teaching him to feed himself. The mother of a very severely handicapped cerebral palsied child said that she could not bear her own mother to be present when she was feeding her daughter as she kept accusing her of being cruel. Caught between the advice of the professionals on how to help her child and her own mother's accusations of cruelty, the young mother was made to feel very unhappy and she doubted if she would ever be able to teach her child anything. Then her decision to use short-term care created an impossibly tense relationship between her and her mother.

The idea of short-term care in a hostel, hospital or with a 'foster' family, could make grandparents feel very rejected. Some of the parents who were visited described grandparents as 'very hurt and upset' by short-term care and saying that they would have looked after the children rather than let them 'go to strangers' and making accusations about 'putting the child away'.

> 'Dad's parents really disapprove of the hostel.' (Mother of a nine year old boy regularly using a local short-term care hostel.)
>
> 'They always say we're sending her away and don't care about her.' (Parents of a seven year old girl with Down's syndrome).
>
> 'Mum-in-law doesn't like Keith going away. She always says that it's not necessary for him to go there and that she could always look after him instead.' (Mother of seven year old Keith.)

Grandparents' acceptance of short-term care sometimes depends exactly on *where* it is given; if the placement is in a holiday home a long way off they are perhaps happier about it because they see it as 'a holiday' for the child, but regular care given in a local residential facility or with a 'foster' family seems more like the sort of help they could give themselves and this makes them feel very rejected.

Grandparents were sometimes quick to find faults in the quality of care given in units, and if the parents themselves were having a few qualms about using a residential care service they felt even less confident if they also had to face their own parents' criticisms of the care.

If the grandparents were living a long distance away they sometimes had no idea what short-term care meant and they thought their sons and daughters were having the children sent away permanently, although attempts were made to explain it on the telephone or in letters. It was helpful when the facilities had leaflets about the care and the purpose of the help. The parents could then send one to the grandparents to help them understand what short-term care was all about.

One of the single parents in the study had particular problems regarding the use of short-term care, as her mother had always wanted to take much more responsibility for the care of the handicapped child. After the short-term care arrangements were made, when the boy was aged ten, the grandmother did not speak to her daughter for three months. However, not all grandparents were upset about the service. Many were glad that the families were receiving the support, and they would often help with transport and also visit the children in the hostels and hospitals if the parents were on holiday at the time.

It is understandable if grandparents get upset about short-term care and do not understand its aims. When they have looked forward to having a grandchild and then realise that he is going to be permanently handicapped they are not only distressed for their sons and daughters, but for the child also; and they grieve for the loss of the able grandchild they looked forward to so happily. They may even feel they have lost status amongst their contemporaries who are rejoicing in more able grandchildren. It would certainly seem that grandparents need helpful explanations and support if they are to adjust to the situation and make a positive contribution to the child's care and acceptance in the family, and it is a pity if short-term care adds to the pain already suffered by grandparents and increases the likelihood of family discord.

In view of the likely misunderstandings between families and grandparents about the nature of the children's handicaps and the services available and how they may be wisely used, it appears that professionals could profitably give more attention to the role of grandparents in families where there is a handicapped child. Perhaps it would be possible for grandparents to be included in some of the explanations given to parents when the handicap is diagnosed, so they may get early understanding of the problems and can consider what contribution they will be able to make in supporting the family. Perhaps some of the tensions in family relationships might be avoided if grandparents could have opportunities to talk about their worries, which may be caused by confused ideas about handicapped people and prejudices which they have carried from childhood when people with mental handicaps were known as 'idiots' and considered to be dangerous or objects of pity or fun.

Summary and conclusions

It is likely that short-term care causes as many problems as it is supposed to alleviate. In its present form it is too crude and simplistic, *too much based on the idea of separation being good in itself*, with a denial of the warm normal affection that parents feel for their handicapped child and the difficulties they experience in letting them go. It is offered too casually, with little attention being paid to the worries that parents feel about it.

The pressure which is put on parents, by professionals and other parents, to use a facility which means separating from their child, may deny their love for the child and the child's normal need for a secure family life. It may also deny the likelihood of homesickness. Although it is helpful for parents to reassure each other about a facility, it is not beneficial if they over-sell the idea of short-term care to each other and fail to recognise the existence of deficiencies in the service, and the fact that some parents wish to keep their young mentally handicapped child at home.

Can a service that is built on ignoring the normal feelings of parents and children ever be a success? Many parents are denying their misgivings about short-term care and their realisation that the experience probably has adverse effects on the children. Most parents use short-term care again and again without ever discussing their worries with the professionals who plan and manage the service.

Most professionals expect families to enjoy themselves when their children have short-term care and they feel let down if the parents find fault with the service, or say it makes them feel worse or makes their child worse: there is little sympathy for complaints about a service that is supposed to be enjoyed.

Parents need some follow-up after using short-term care, to be reassured that their decision was right and that their child was happy when he was away. This may be done through a visit from the social worker or member of the care staff soon after the child's return home, or by the parents themselves going to the unit to talk to the staff. A note or a telephone call from the staff may be helpful to say what the child did when he was away, to reassure his parents that he was not lonely or bored and that somebody on the staff was noticing him. In one unit the staff put a note in the children's cases when they went home so that the parents could read about what they had done during their stay. This was a means of making a positive link with the parents who were unable to get to the unit very often. When there are no links between the staff and the families, the parents may feel increasingly worried, and even guilty, about using short-term care. (For particular reference to parent/staff links see Chapter 5.)

Generalisations should not be made about short-term care always being of great benefit to the siblings of handicapped children. It is possible that the affection and companionship that exists between siblings and the handicapped child, especially in infancy, is being underestimated by professionals. And it should never be assumed that the more handicapped a child is the more welcome will be his absence. The most dependent children and those with behaviour disorders may be the most sadly missed by their brothers and sisters.

The ages of the handicapped child and his siblings and their position in the family are significant. The normal stresses and intolerance of adolescent years seem to make the absence more welcome, but when the siblings are in infancy the absence of the handicapped child appears to be quite threatening. The siblings may be made anxious and lonely when the handicapped child goes away, and they may show their anxiety by disturbed behaviour.

If parents and professionals over-emphasise the advantages of short-term care they may create a poor image of the handicapped child and prejudice the siblings against him.

There is a need for constant reviews to be made, not only on the use of short-term care but also the type of short-term care preferred. During the children's infancy, a good sitting-in service may be preferable to residential care, but the use of a residential facility later on may help handicapped adolescents to become more independent as well as giving relief to parents. The help needed by parents when the handicapped child is aged four and has a sibling of two years old may be quite different from what is needed when there is a handicapped child of 14 and a sibling of 16. Service planning should consider the families' interrelated needs at different stages in family life rather than the single fact that one of the children is handicapped. *Errors lie in planning a blanket service based solely on arrangements to separate, rather than on principles of meeting the normal and fluctuating needs of parents and all the children in the family.*

The use of short-term care may be influenced by the degree of contact that parents have with their own parents. Parents may make less use of the short-term care facility if the grandparents live nearby and are able to help. Elderly, frail grandparents and those who live a long distance away will not be able to help with the handicapped child and may even need support themselves, which makes the use of short-term care even more necessary for the handicapped child. Sometimes the grandparents are made anxious and unhappy about the use of short-term care, feeling rejected because they have not been asked to have the child, or worrying in case the child will be 'put away' for permanent care.

There is a need for more positive links to be developed between *all* members of the family and the residential care facility, instead of just crudely arranging a separation based on loose assumptions that the family will have 'a more enjoyable life' because short-term care has been organised. The following chapter discusses in more detail what parents feel about the services they are receiving.

4 Parents' opinions about short-term residential care services

> 'We put up with what we are offered, we need help, we are grateful for it, but that is not to say that we like it.'

This chapter looks at whether the parents' initial worries about using short-term care were confirmed by their experience of it, what they disliked and liked about the particular facilities they used, whether they thought they would make continuous use of short-term care, and how they thought the service might be improved.

Confirmation of initial worries

Table 5 refers to the answers given to the question, 'Have your initial worries proved justified?' by the 81 parents in Group A (who were using the four main facilities visited during the study). Half said that their experience of short-term care had confirmed their initial worries and that the worries were continuing. Seven parents who had started off very trustingly and eagerly, thinking that they would never have any worries about using the services, developed dislikes about short-term care after they had experienced it a few times. It is interesting to note that the initial practical and emotional worries expressed by parents at the idea of using short-term 'fostering' had proved groundless, experience of it reduced initial worries and the parents who used this form of support were finding greater satisfaction than those who were using hospitals and hostels.

Parents' dislikes about using short-term care

A hundred and one parents were asked what they disliked about the short-term care service they were currently using (these were the 81 parents of Group A using the four main facilities visited during the study, plus 20 from Group B who were using Northbridge, a small mental handicap hospital unit provided by the local health authority). Four did not answer the question, 41 said they did not have any dislikes, and 56 said they had. It was a sad reflection on the services being provided that more than half the parents did have dislikes.

When parents had been describing their initial worries about the idea of using short-term care, they mentioned practical concerns such as whether their children would be cold, hungry, hurt, uncomfortable

Table 5 The extent to which parents' initial worries about short-term care were confirmed by their experience of it

Facility	Number of parents asked if their initial worries had been confirmed by use	Number of parents who had practical worries about short-term care before use	Number saying their initial practical worries had been confirmed by use	Number of parents who had emotional worries about short-term care before use	Number saying their emotional worries about using short-term care were continuing after experiencing it	Number of parents who had no initial worries about short-term care but their experience of it gave them dislikes
Collingwood (NHS)	31	15	7	12	9	4
Rivermead (lassd*)	24	8	4	7	4	3
Field Lodge (NHS)	17	7	6	9	6	0
Middleshire fostering (lassd*)	9	7	0	6	0	0
TOTALS	81	37	17	34	19	7

Total of parents having practical and emotional worries before use: 71
Total of parents having their practical and emotional worries confirmed and continuing by use: 36
* Local authority social services department.

at night (see pages 54–56). Their answers to the question, 'What do you dislike about using short-term care?' showed that many of these worries had been *confirmed by use* and *were continuing*. In fact, regular use of short-term care had all too often changed the parents' initial worries into chronic dislikes.

> 'He *always* gets sores.'
>
> 'He comes home exhausted.'
>
> 'She is tired and hungry when she gets home.'
>
> 'She had scratches on her and nobody told us or seemed to know how they happened.'
>
> 'He does not get enough to drink there, he seems dried out when he comes home.'

Table 6 shows the nature of the parents' dislikes in relation to the facilities being used.

Parents' dislikes are described in more detail below, and are grouped under seven broad headings. Some of the 56 parents with dislikes referred to as many as four of the seven.

1. *Dislikes relating to the care of their children*—poor physical care, not enough play, upsetting the children's home routines, the children being cold, dirty, hungry, thirsty, scratched, tired (mentioned by 34 parents).
2. *Dislikes connected with staffing*—poorly qualified staff, difficulties in making contact with them, their organisation, their unfriendliness, over-use of volunteers, too many changes of staff (mentioned by 22 parents).
3. *Dislikes related to the experience of separating from their children*—the anguish of leaving them, not knowing how best to do so, getting them to the facility, the sense of loss when they were away, the house feeling empty and the family routines not the same (mentioned by 18 parents).
4. *Dislikes about the availability of the service*—difficulties in bookings, worries about whether the services would be cut, not being able to get their child in during August (mentioned by 13 parents).
5. *Dislikes about the mix of children in the facility*—wondering if the frail ones would get hurt, mixing teenagers with much younger

Table 6 Parents' dislikes about short-term care

Facility used and the number of parents questioned	Number of parents who said they did have some dislikes	Number of parents who said they had no dislikes	Number of parents who did not answer the question	The nature of parents' dislikes			
				Number with dislikes related to child care, staffing and organisation of the care	Number with dislikes related to separating from their children	Number with dislikes related to availability and/or booking the service or its likely termination	Miscellaneous dislikes—eg, mixing sexes, dangers in environment
Collingwood (NHS) (31)	22	8	1	17	8	6	1
Rivermead (lassd*) (24)	10	13	1	6	3	1	1
Field Lodge (NHS) (17)	11	6	—	9	5	0	3
Middleshire fostering (lassd*) (9)	2	7	—	0	1	1	0
Northbridge (NHS) (20)	11	7	2	5	1	5	3
TOTALS (101)	56	41	4	37	18	13	8

* Local authority social services department.

children, too many 'over-active' children (mentioned by 12 parents).

6 *Dislikes about the care and organisation of the children's clothes*—lost clothes, not being able to wear their own clothes (mentioned by ten parents).

7 *Dislikes of a miscellaneous nature*—dangers in the environment, such as large windows and low electric plugs, mixing sexes in the bedrooms, too much free play (mentioned by eight parents).

There seemed some connection between parents' *practical dislikes and their family circumstances*. For instance, parents who had long-standing problems of housing, unemployment and poverty, tended to be less critical of their children's physical care than were the more financially secure parents. Perhaps this was because they were already overwhelmed with multiple problems and were glad to know that their handicapped children were at least accommodated in what appeared to be a warmer, brighter and more comfortable environment than they were able to provide. And ten out of the 16 single parents in the group who were asked about dislikes said that they had none regarding the children's *practical care*. The tendency of single parents to be rather less critical of practical issues possibly indicated their need for support, their wish for it to be successful and a reluctance to criticise what they were offered, because they were more dependent on help than parents with partners.

Parents' dislikes about the emotional trauma of separating from their children showed no relationship to family circumstances. Their affection for their children and their sadness at separating from them was not lessened because of difficult home circumstances such as single parenthood, ageing parents, numerous siblings, poverty, poor housing and unemployment. This casts doubts on the assumption, made by many professionals, that families with social problems will welcome any sort of short-term care.

Two significant conclusions to come from the answers about dislikes were: first, how the dislikes related to the type of facility, its inception, organisation, siting and the degree of contact between parents and staff; and second, the deep concern that parents felt about the experience of separation. This concern, which was of major importance for the parents, did not seem to be sufficiently recognised by the professionals.

Regarding the connection between parents' dislikes and the type of facility being used, their answers showed that residential care provided in hostels and hospitals always presented certain difficulties. There were a total of 78 references to dislikes about the practical care of the children, the staffing and the organisation of child care. These were made up of: 32 references to Collingwood (the health authority unit sited on an ex-fever hospital), 27 to Field Lodge (the new mental handicap hospital sited behind an old general district hospital), ten to Rivermead (the new local authority hostel sited in an ordinary street); and nine to Northbridge (a health authority unit sited in a ward of a hospital no longer used for sick patients). None of the parents using the Middleshire fostering scheme had dislikes regarding the practical care of their children.

The following remarks were typical of what parents disliked about short-term care provided in hospitals and hostels:

> 'Last time we went to pick her up she was lying on the floor and stinking. She'd not been changed. And the staff were sitting in the ward kitchen drinking tea, and a young girl volunteer had been left sitting with the children in the playroom and they were all just lying around on the floor doing nothing.'
>
> 'He's never dressed warm enough like we keep him at home. He can't move around to keep himself warm, he can't walk or anything but they don't seem to understand this. They leave off the wool tights I always put on under his trousers. He comes home cold in the winter and sometimes in other children's clothes.'
>
> 'I'd been told before he went there that the place would be like a children's home, with houseparents—but it's not. The staff sit about and they don't play with the children. There's never any play activities at all.'

Although parents were acutely aware of the poor standards of child care, they sometimes had a curious acceptance of it and did not often seek explanations or make their dislikes known to the professionals. This might have been because they did not have any channel for expressing opinions or criticisms, and they were wary of complaining about staff behaviour in case they caused offence and made life difficult for their children. But even matters which could only be seen as a comment about the buildings, such as electric plugs being accessible to children, large expanses of glass, or gates to dangerous roads not being fastened properly, were rarely discussed with the professionals who might have been able to change things.

Parents even tended to accept with meekness the serious matter of keeping children away from school unnecessarily when they were in short-term care, although they would have been well within their rights to ask for an explanation on grounds of legality alone, quite apart from the upset in routine that an absence from school could cause the children. In one hospital unit the children were kept away from school one day each week so they could be seen by a doctor, but the parents did not complain about this although they did not like their children missing school. This medical check-up was unnecessary because the children were not sick patients, but it seemed that the organisation remained bound up in traditional medical routines in spite of purporting to be developing a new role in the provision of residential care and family support.

The connection between parents' dislikes and the inception of a facility was sharply illustrated in the setting up of Field Lodge, the new mental handicap hospital. Parents had not been involved in its early planning as it had been part of a long-term regional health authority plan, and their means of getting information about it was mainly through newspapers and conducted tours of the hospital after its completion when they were given descriptions by consultant psychiatrists, social workers and nurses about what sort of help the hospital would provide. The professionals had an image of the hospital being a 'resource centre' into which the families would be slotted for life-long support. However, instead of this concept of total care inspiring the parents with confidence, they felt very frustrated about the services they were receiving. It was significant that the parents using Rivermead, the local authority social services hostel, who had been informed early about the plans and organisation, had fewer initial worries and subsequent dislikes than those who were using health authority facilities.

Another explanation for greater dissatisfaction amongst parents using units on health authority sites than amongst those using the local authority hostel in an ordinary street, is that large health authority sites do not facilitate contact between parents and staff. If the health authority units are not very accessible to parents this may mean that their introductory visit and subsequent contacts are difficult to arrange. (Reference to the importance of locally based units was made in Chapter 2, pages 42–46.) And, in addition to their siting, the organisation of the larger health authority units, with their tradition of hierarchy, staff movement and student training, are likely to preclude continuity of contact between staff and parents.

Many of the parents met during this study did not know the names of the staff who were caring for their children, although they had been using a facility very regularly for two or three years. (See Chapter 5, pages 118–128). One result of the poor communication with parents was that the staff were unaware of their dislikes about the care so they did not try to change anything. Efforts to form parent/staff associations, which might have discussed family worries, usually foundered and had few aims other than fund-raising. (See Chapter 5, especially pages 144–147.)

Extensive use of a facility, when one might have expected good contact to be gradually developed between parents and staff, did not necessarily lessen parents' dislikes—indeed, it sometimes created more. The Osborne family started using short-term care without any worries at all, but developed many dislikes during the two years that they were making very extensive use of a health authority facility for their teenage son who was very severely multiply handicapped. He had one to two nights short-term care every week all through the year, but although his parents very much appreciated this because it enabled the mother to visit and give regular weekly help to her own ailing and elderly mother, they spoke of feeling an increasing dissatisfaction with the shortcomings of the unit—the staff, lack of communication, transport difficulties between school and home and the unit, the children's day-time activities there, dangerous heaters on the wall, and lost clothing.

Other families who had been making extensive use of short-term care also spoke of increasing dislikes about quality of care.

> 'There is a lack of staff for indoor things and activities on winter days and wet days for children who are very handicapped and can't play on their own. The more helpless children are left alone too much, just lying about.' (Mother of an able boy with Down's syndrome. He was capable of playing on his own, but his mother always felt very worried about the physically dependent children who never seemed to have any attention or activities.)
>
> 'The television is on all the time and she sits just sucking her hands. She'd forget how to walk if she was there long.' (Father of a girl with Down's syndrome, very poor sight and some difficulty in walking.)
>
> 'The staff, as far as we can tell, are not qualified. They call themselves nurses and lounge about all the time. We don't like all the girl guides who come into the ward and just take over and feed the children. We worry all the time about what is happening to him as he is so helpless and could choke.' (Parents of a multiply handicapped boy.)

The parents quoted above had been to the hostels and hospitals and actually seen things that they did not like. The following parents had rarely been to the units where their children had short-term care, but they did not like the condition in which they were returned home and they did not think that any of the basic principles of child care were being met: that is, cleanliness, clothing, suitable play activities, enough to eat and drink.

> 'She is hungry and thirsty, and drinks and drinks when she gets back home.'
>
> 'I can tell he's had nothing to do and that he's been sucking his hands all the time.'
>
> 'His clothes are always put on all wrong.'
>
> 'She has a special smell, dirty, about her when she comes back from that place.'

Looking at the second significant conclusion about parents' dislikes—*the emotional trauma of separating from their children*—18 parents made 23 references to *specific dislikes* connected with this experience. Remarks like the following were typical:

> 'Part of me is gone when he goes up there for a couple of nights.'
>
> 'What I dislike most about short-term care is feeling guilty about it, about sending him away.'

In Chapter 3, pages 54–55, reference was made to 51 parents having worries about separating from their children. The parents using Rivermead, the local authority hostel sited in an ordinary street, made fewer references to dislikes of an emotional nature. This was probably because Rivermead staff had consciously tried to give parents some confidence about the separation by introducing the children very gradually to being away from home and letting the parents make informal visits beforehand. This approach was, of course, easier in the locally based Rivermead hostel than in hospitals serving a large catchment area, or in 'holiday homes' miles away from the children's families. Parents using large remote facilities seemed to be suffering more stress and receiving less help from staff with regard to the problems of separation.

Parents' references to emotional stress suggest that they lacked opportunities to express these particular worries during their introductory visits and in later contact with staff. If staff fail to acknowledge the parents' stress, this may also have implications for the children: for example, their homesickness may be unrecognised. Parents and staff alike may deny the children's feelings about the separation and how the experience may upset them and result in unhappy behaviour when they return home again. (For more about children's homesickness see Chapter 6.)

> Mr and Mrs Rowland had very poor communication with the staff of the mental handicap hospital ward that they were using for the short-term care of their nine year old son Quentin. They felt unable to discuss with staff the painful issue of separating from their son, and they subsequently realised that they were also denying their child's feelings about the separation simply because they felt so helpless to do anything about it. It seemed that the only thing they could do was to pretend that his homesickness did not exist.

What was happening to Mr and Mrs Rowland and nine year old Quentin was all too common. It seemed as if short-term care could be responsible for setting up a *cycle of stress*: parents and staff had poor contact with each other, there was a denial of the children's feelings by the parents who *themselves* felt stress, this in turn created more stress for the children. This was not acknowledged and discussed by staff because there was a failure to recognise it in the first place. As the whole point of short-term care is to relieve stress, it is very unfortunate if weaknesses in its organisation create additional stress.

Significantly, the practical and emotional worries and dislikes referred to so far were not occurring amongst parents using the short-term care 'fostering' schemes, and this suggests that the problems were caused because services were organised on a large and impersonal scale. Short-term care in an institutional setting tends to be primarily a *kennelling of children*, providing a means of separating them from their parents but not giving staff any opportunity to build up the reassuring relationship which is encouraged in short-term 'fostering', where there is a clear philosophy of offering help through the development of a caring bond between the child, his family and the substitute family. The parents know the fostering family and can speak to them if they telephone or visit, unlike hospitals where there always seems to be somebody different looking after their child. And a major advantage is that the fostering parents do not work duty hours and hand over the child to other staff. The security and personal service of fostering makes it a very popular form of short-term care, with none of the problems inherent in caring for children en masse. (For more about short-term fostering care see Chapter 8.)

Some of the emotional traumas experienced by parents using short-term care were not necessarily caused by the type of facility. Mrs Maddison described her child's short-term care unit in glowing terms and she obviously had a good relationship with the staff, but she felt completely lost when her son was away. He was gravely handicapped, physically and mentally, and needed everything done for him. He was unable to walk or talk or hold anything in his hands, and was blind as well. His parents' life-style, day and night, was shaped by his need for care and Mrs Maddison said that she could not bear the feelings of loss when he was away:

> 'I miss him all the time – it takes me time to adjust. I'm always so clock-bound when I'm looking after him, and when he goes away I don't know what to do with myself, with my hands, I feel lost.'

No matter what facility his mother had used for short-term care, she would doubtless have felt the same sense of loss during the absence. Other parents referred similarly to being devastated by the absence of a child who needed much care: 'The suddenness of the freedom is quite frightening', said one mother. Such reactions challenge planners' assumptions that the more handicapped a child is the more the parents will welcome short-term care; indeed, the parents of the most dependent children often seem to find the most difficulty in adjusting to their absence. (This also applies to siblings, see Chapter 3 pages 65–67.) To feel conflict about being 'free' is understandable. It is therefore essential that the quality of the short-term care is good and does nothing to make parents feel that their decision to have periods of separation from their handicapped children is likely to harm them.

Two families felt emotionally distressed about using short-term care because it awakened fears about their children's futures. Every time they took their children to the mental handicap hospital for short-term care these parents noticed the adjacent adult wards and the deprived and lonely lives led by many of the adults as they wandered aimlessly about the hospital grounds, and they visualised their children growing up to lead similarly lonely lives in adult wards because there was no other form of care available in the area.

The segregational aspect of providing short-term care in 15 or 20 bedded hostels and wards was mentioned as being disturbing for siblings (see Chapter 3, pages 74–75). It can also be disturbing for parents. The mother of a three year old, multiply handicapped girl said:

> 'Dad does not like her going up the short-term care place, he gets upset at seeing her with other handicapped children. It makes her seem more handicapped. He likes to think of her as normal. He won't go there himself. He went once but never again.'

It is understandable if parents are upset at seeing large groups of handicapped children when they first visit the units their child is going to use. They may feel worried that an active child will frighten their own child, or that the child will hurt a more helpless one, or they may be saddened when they see handicapped adolescents for the first time and realise that their own small child may be like that in a few years time. Parents have few opportunities to discuss these feelings with staff or social workers. After using the units and getting to know the other parents and children as individuals they generally feel less upset, but more might be done to ease these sad feelings in the early stages of introducing short-term care. (See Chapter 5 regarding parents' contacts with units.)

However, in spite of the many worries and dislikes associated with short-term care, when the 101 parents were asked if they would advise other parents to use the services, only one was emphatic that she would never recommend it to anyone else. One parent said he 'Could not speak for the other people, but it is OK for us'. Fourteen did not answer the question. The remaining 85 said they would definitely recommend it to other parents.

To recommend a service about which they have so many dislikes and suffer considerable heart-ache suggests that parents require support in caring for their handicapped children, although they feel very ambivalent about what is being offered. It suggests, too, that parents probably cherish an ideal about support services and perhaps find it difficult to reconcile themselves to the reality. Perhaps in recommending it to other parents they seek to justify their own use of a poor service. They could hardly say they would not recommend to others a service which they were regularly using themselves. Using a service about which they are not completely happy, parents are likely to get carried along on a wave of impotence, and because they want to feel that they have made the right decision for their children they eventually find themselves defending the poor service and even recommending it to others.

The ambivalence parents feel about their short-term care services suggests that planning should be far more parent oriented.

> 'We find it useful but it is not really what we want for her.'
>
> 'We hate it but intend to use it forever I suppose, as there's nothing else.'

These remarks sum up the conflicting feelings that most parents had about the services they were using. Would they have been happier with support provided in the home rather than a total separation from their child caused by overnight stays in a hostel or hospital? Would they have preferred using a 'fostering' scheme? Had they ever been asked what they wanted?

What the parents liked about short-term care

A hundred and one parents were asked what they liked about their short-term care services. Four did not answer the question. Five said that there was nothing they liked. The other 92 listed their likes, some naming several and others only one.

Table 7 What the 92 parents said they liked about short-term care

	Number of parents
The freedom it gave	54
The quality of the children's care and/or it was of some advantage to the children	30
The environment of the facility	18
The staff	14
It was a chance for them to give attention to the siblings	11
The flexible way it was organised	9
The mere fact that it existed	5
It was 'geared to parents'	1
It was a chance to give attention to husband	1

The parents used the word 'freedom' in a very broad sense, usually meaning the opportunity for a rest and a general feeling of relief. Some parents saw this 'freedom' as a chance to be 'selfish' for a little while.

> 'I can have a bath without being interrupted.'
>
> 'I can read the paper in the morning on a Sunday.'
>
> 'I can have a lie-in.'
>
> 'I can clean the car and leave the gate open and the bucket of water out.'
>
> 'I can warm my bum at the fire without having to have that great fender there.'

Short-term care for one family meant they could relax from the constant vigilance required to prevent their very over-active child getting out of the door and running off.

> 'When the older kids' friends come visiting we can let them in the front door properly and leave the door open for a little while. There is not that mad scramble to let them in a crack and slam the door in case he runs out and hurtles off.'

Mr and Mrs Fields liked short-term care for giving them a chance to go on outings that would not be possible for a child in a wheelchair, and during their interview they described a momentous and absorbing day when they visited a tin mine. They said that having been restricted for many years because their multiply handicapped daughter Tess was confined to a wheelchair, their visit to the tin mine was 'as exciting as a trip to the moon'.

The answers showed how even the most loving parents may become emotionally and physically tired when caring for a child who is severely handicapped. Even if the child is not resented and is dearly loved and part of the family circle, his care may make many demands on his parents' time and patience. There is the physical work and patience required when caring for a totally dependent child like Mr and Mrs Fields' daughter, the dull and binding routines which may be necessary to keep the home happy and controlled for a child with a behaviour problem, the feeling of restriction caused because it is impossible to withdraw from the child long enough to relax. Parents may appear to be calm on the surface but they may need time on their own to recoup their energy. Good quality short-term care can help to relieve their tension. The following two mothers, both divorced and aged in their mid 40s and coping on their own with severely handicapped adolescents, wrote describing what short-term care meant to them:

> 'It is a great relief, as I sometimes get under considerable stress. I can get out with my other child and enjoy country walks and shopping. I'm more able to relax and sleep at nights. I am able to cope better when she comes home again because I've had that rest.'

> 'Short-term care helps me to keep my child at home for longer, otherwise full-time residential care would have to be arranged. I like it because it helps me to enjoy the world outside free from worry. The usual timetable becomes non-existent, a complete change from the routines that he loves and demands. I like having longer time in bed in the morning. I can show greater patience with him on his return.'

Until short-term care was available many of the parents had been worrying about what would happen if they were ill or had an accident, fearing that whilst their other children would be cared for 'somewhere ordinary' – with neighbours or relatives or in a temporary foster home – their handicapped child was at risk of being placed in some sort of 'mental institution'. Parents living in districts where community services had not been developed had the bogey of the long-stay mental handicap hospital always hanging over them, and their apprehension was frequently made worse by reports of poor care in such places.

> 'Before the hostel opened I used to lie awake worrying about what would happen to her if I burnt myself. But she is known to the short-term care hostel now so if I have an accident she would go there till I was better.'

> 'Before the short-term fostering scheme started there was nothing, only the mental hospital. Then I was so worried about him, who would look after him if anything happened to me. If I'd had a lump in my breast I would never have mentioned it to anyone in case I'd had to have an operation and he would have to go away to the mental hospital.'

The 30 parents who said they liked the quality of care or thought that the short-term care benefited their children in some way (Table 7) referred to examples such as: the children were encouraged to be friendly with each other, they had good food, the school teachers and care staff cooperated in booking-in children who were friends so they were together and got more fun out of their stay, the children were able to go to their own schools when they were away (attendance at their own school not being possible if the short-term care facility was in a different area).

Quality of care was especially referred to by those parents who had used more than one facility and found that standards varied widely from place to place.

> Mrs King's four year old daughter, Lara, was multiply physically handicapped and blind. When she was two years old her parents had been persuaded to let her go for short-term care to Moor Grange mental handicap hospital. Here she had been 'left in her cot for ages and never picked up; and she was put into hospital clothes. She got ill and we were not told until we went to fetch her and we found her all unkempt. The new hostel is more like a holiday home and the staff take trouble with the children to see that they are cared for like the parents care for them'.

Within the group of 30 parents who liked the quality of care and thought that short-term care benefited their children there were seven who said that they liked it because their children liked it. Three of these said:

> 'We like it because our boy likes it there. He likes the company of the other children.' (Parents in their 40s with a teenage son with Down's syndrome, using Northbridge mental handicap unit.)

> 'She's happy there, so I like it.' (Grandparent caring single-handed for a 17 year old, mentally handicapped grand-daughter using Field Lodge mental handicap hospital for short-term care.)
>
> 'She likes it and does not mind going in there. She likes all the play activities.' (Parents of a seven year old daughter using Rivermead, the local authority short-term care hostel.) Whilst we were talking during the interview the little girl got out of bed and came into the sitting room and when we asked her about Rivermead she smiled and laughed and said 'Water. Bubbles. We play in the bathroom with the bubbles. Colour telly there. We go shopping. I take my case. I play with the water there and with Suzie. I take Paddington Bear to Rivermead with me. I play with Julie and Suzie.' She obviously felt happy about her stay in Rivermead and the parents liked knowing that she was happy there.

It seems a sad reflection on the quality of short-term care services that only seven parents out of 92 felt able to make the point that their children liked it, and it was significant that four of the seven were in the group of nine who were using short-term fostering families. They described their children's reactions:

> 'We like the scheme because he has made such a good relationship with the family and he likes them and staying with them.' (Parents of an over-active, mentally handicapped boy aged 14.)
>
> 'He's happy with the Browns, so we can go away happy. In other places we have felt he was unhappy, hostels, hospitals and places, but the Brown family is wonderful and he likes the company of their two sons.' (Elderly parents of a boy with Down's syndrome in his late teens.)
>
> 'He likes staying with Mrs Patterson, he charges up to the door and rings the bell when he gets there. We say to him you are going to Mrs Patterson and he says "Pat, Pat" and laughs and gets excited and pleased.' (Parents of an over-active, eight year old boy.)
>
> 'I want to use the scheme for as long as possible, regularly. It is marvellous, she loves it there. I was worried at first, but now I know she loves it. She plays with *normal* children there. Here there is only me to play with her and at school only other handicapped children. She calls Mrs Singer, Aunty, quite naturally and is one of the family there.' (Mother of 12 year old, mentally handicapped daughter.)

It is significant that parents using the fostering scheme always referred to liking the warm relationship which formed between the fostering family and their child. They saw this as very important. Short-term fostering schemes have developed a firm philosophy of providing support through the formation of good relationships between the child and the parents and the foster family, unlike the more traditional forms of care in hospitals and hostels where, for a number of reasons (for example, changing staff, large numbers of children), it is difficult for children and parents to form close personal relationships with staff.

The advantage of 'mixing with normal children' was continually stressed by parents using fostering schemes. For some of their children it was the first opportunity they had ever had of being with children who were not handicapped.

> Mr and Mrs Carter's only child, Paul, was very over-active, with limited speech. He had no companions at home when he returned from special school and he tended to stay indoors because as he had become older and more active he was more of a problem with regard to playing outside. He was 11 years old. Because he had no brothers or sisters or cousins and did not play with neighbourhood children, he never saw children without handicaps. The only children he was ever in contact with were those at his special school, handicapped like him. When the fostering scheme started his parents did not think he would be able to use it, but they were overjoyed when it was arranged for him to have regular weeks with the Brown family, where there were two children of his age. Mrs Carter described the advantages of him going to 'a normal family': 'At home here he only ever sees me and his Dad, adult company all the time, and at school there are all handicapped children, so it's marvellous that he can mix with Mr and Mrs Brown's two boys. When he comes back he seems to have improved in lots of ways, better at the table and more speech too. We know that he likes it there.'

(For further discussion about fostering see Chapter 8.)

Five of the 30 parents who said they liked the quality of the care or thought that it benefited their children mentioned that it was good for the children to have an opportunity to 'get used to being away' because one day they might have to live away from home altogether if their families could no longer look after them. All five had some reason to be acutely aware of their children's uncertain future; they were older parents and/or single, or unwell.

Mrs Gittings, widowed mother of ten year old Mark, summed up the worries of parents of handicapped children regarding the future:

> 'I look on short-term care as getting him used to being away from home, because if anything happened to me and he'd never been used to anyone else it would be such a shock for him.'

Mrs Gittings' worries were coloured by the attitudes of society towards handicapped people. At the back of many parents' minds is the thought that their children are not really accepted by society and are always at risk of being 'put away' and misunderstood. It is significant that ordinary children are not expected to go away from home in preparation for their parents' death. Despite the many changes in attitudes towards handicapped children in the last decade, the notions commonly held about their upbringing and needs still differ widely from those held about ordinary children, and the use of short-term care is a classic illustration of how they are still being regarded as 'different' and not having the same feelings as ordinary children.

The youngest child of the five referred to above was Victor White, he was only six but his mother thought that the short-term care was good for him and she liked it because:

> 'It gets him used to being away from home because one day he may have to go away altogether because of an accident or something like that happening to me—illness or something.'

Mrs White felt that her son was particularly vulnerable because she herself was severely disabled by arthritis and so was her 13 year old daughter. She felt at risk of total incapacity as her arthritis was worsening and she understandably wanted Victor to get used to being cared for by other people. He was having regular short-term care in Rivermead, the local authority hostel.

The five parents referred to above had obvious reasons for wanting their children to get used to being away from home, but the argument that short-term care is always a good preparation for future independence is used in a very arbitrary fashion by some professionals when advising parents to use it and by some parents who want to justify their decision to do so. The argument might be valid for adolescents but should be stringently queried with regard to putting children as young as five or six into short-term care. There is no reason to suppose that handicapped children have a greater need than other children for very early and intensive preparation for growing up and leaving the family home. It is curious that the example of boarding school is often cited in arguing the case for residential care for very young handicapped children, although boarding school is not customary for five or six year olds in late 20th century Britain and is, indeed, now suspected of causing stress at any age. As already mentioned in this report, to recommend residential care for young children *because they are handicapped* implies that they are less likely than normal children to be hurt by separation from their families and therefore do not merit normal considerations. If sound principles of short-term care are ever to be formulated there is a need for everyone involved in its organisation and provision to question the assumptions put forward in support of it; for instance, before advocating short-term care as a desirable means of preparing mentally handicapped children for independence, it would seem essential for professionals and parents to ask themselves whether the child in question is at an *age* when he would be normally getting 'prepared' for leaving home and 'prepared for independence'?

The following mother did not describe short-term care as specifically being a 'preparation for adulthood' but she nevertheless appreciated that it gave her two handicapped daughters a chance to 'grow up'.

> Mrs Hill was a widow in her mid 50s and she had two daughters with Down's syndrome, aged 11 and 12, the youngest one being adopted. She had been widowed for three years and had recently started using the local authority hostel, Rivermead. She said that the two girls always went together and although they had not been too happy about it at first they now looked forward to it. 'They have really grown up since they have been going, the youngest one always wanted to sleep with me but now they share a bedroom at home like they do at the hostel. And they want their bedroom to look like the one at the hostel, with bookshelves and twin beds and posters, much more like coming up to teenage. I notice a great difference in them since they've been going up there.'

The sort of short-term care experienced by Mrs Hill's daughters was obviously very positive. She was adamant that she 'would not just send them anywhere to give myself a break, it's got to be right for *them*'.

Two mothers said they thought short-term care was an advantage to their children because it prevented them going into long-term care. 'He'd have to go away for good if he didn't have Collingwood for short-term care', said one of the mothers. She was living in an unsuitable upstairs flat with no front garden, and her problems were exacerbated by poverty and her husband having left her. She was expecting to be rehoused and hoping that her husband would return, and in the meantime she saw short-term care as helping her over a very difficult period in her life and preventing her eight year old child from having to go into long-term care.

However, the popular notion that short-term care *always* prevents long-term care is little more than a loose assumption. There is no proof that it does. Indeed, the 1978 study of children in long-stay hospitals[1] suggested that periods of short-term care might precede and lead to long-term care. And an examination of children's records in this present study showed that the short-term care of some children steadily increased over the years and was the prelude to their admittance for long-term care. Whether the short-term care was badly provided and disturbed the children and made them even more difficult, causing more demands for short-term care and eventually a request for long-term care, *or* whether the first use of short-term care was in itself an indication of a family's unconscious, or conscious, wish to relinquish their child to long-term care, nobody could know. But what is certain is that short-term care once started does not *decrease*, it either stabilises or increases. Only one family out of a 100 who were using one short-term care unit had actually cut down on the periods their child had been regularly having for two years; his parents thought that he did not need to be away from home so much as he was becoming less difficult and their other children had grown up and left the family.

With regard to discovering whether short-term care does actually prevent long-term care, I would suggest that any investigation into this theory would need to take into account the type of place being used for the children's short-term care and the quality of the care they were receiving. I would go so far as to postulate, from examination of children's records and observations of their care, that badly organised short-term care will inevitably cause disturbances in the children's behaviour (as mentioned above) and will result in a cycle of increasing separation requests from the parents and increasing unhappy behaviour from the child, which will eventually lead to them having long-term care. One family said that they found short-term care more to their liking than long-term care because it meant 'our child still belongs to us although he's away such a lot'. Their eight year old son was receiving massive periods of short-term care in a mental handicap hospital, and the father said, 'We feel that he is still ours but *we can put him in and out of hospital as we wish*, and although he is getting more difficult we have not yet had to give him up completely'. This family's use of short-term care was described in very positive terms by the hospital staff, as 'shared care' and 'the best form of community care'.

Two years later that child was having long-term care in the hospital and only going home for occasional weekends. It would seem that his previous massive use of short-term care was, in fact, the prelude to long-term hospital care. This little boy's gradual rejection by his family had been disguised and/or caused by his massive use of short-term care. And how about his feelings? His constant comings and goings from home to hospital and back home again, and then the slide into long-term care, must have been very disturbing for him. His situation suggests that some forms of short-term care are not in the best interests of the children, and that much more supervision and monitoring should take place regarding parents' increasing their use of any facility. The important question is: when are signs of parental rejection recognised and steps taken to call a halt to the cat-and-mouse arrangements known euphemistically as 'shared care' and advise parents that long-term fostering, or even adoption, would be kinder for their child? (For further reference to short-term care drifting into long-term care see Chapter 2 page 42 and Chapter 6 pages 179–180.)

Eighteen parents referred to liking the environment and siting of the facility they used—the homeliness, 'not being like a hospital', 'being small'. They appreciated the efforts that the staff made to decorate the children's rooms pleasantly and the fact that they didn't wear uniforms. Parents who had previously had to use big hospitals a long way away for short-term care always commented on their preference for small locally based units once they were opened; they did not mind whether they were run by the local health authority or by the social services department, so long as they were local and small. Being 'like a children's home' was high praise for any unit.

Fourteen parents said they liked the staff: they were 'friendly', 'kind', 'efficient', 'honest', 'calm'. One parent liked receiving advice about problems from the staff. Only one mentioned liking the night staff. Positive references to staff came mainly from parents using Rivermead, the locally based social services facility where the staff made a special effort to maintain friendly relationships with families. Only one parent using any of the three health authority facilities made a direct reference to liking the staff. This lack of praise for hospital units was not necessarily because the parents actively *disliked* the nurses, it was probably because staff/parent relationships were closer in the social services unit than in the health authority units. In fact, all too often the parents just did not know the staff in the hospital unit, so felt quite unable to comment about whether they liked them or not. (See Chapter 5, pages 118–128 about parents knowing the staff.) Parent opinions of the same staff occasionally varied. Two families using one health authority unit each described the staff in opposite terms, one saying 'we like their friendliness' and the other saying 'the staff are very unfriendly indeed'. It was impossible to draw any firm conclusions about how much the staff and parents did actually like or dislike each other, because there are so many variations in parents' expectations of staff, and in staff understanding of the families' needs and in their attitudes to families. But it appeared that parent satisfaction with staff was greater in the locally based social services hostel than in the health authority units.

Although it is commonly believed that short-term care is very popular because it gives parents the opportunity to pay attention to the siblings, only 11 parents mentioned this. This casts further doubts on the theory that short-term care is essential for the sake of the other children in the family. (This point was discussed at length in Chapter 3 pages 64–78.)

Only one parent, the 31 year old mother of a six year old mentally handicapped girl, mentioned that short-term care was good because it enabled her to give more attention to her husband.

Nine parents referred to liking the flexible way in which the short-term care was organised. Seven of these were using Rivermead, the social services unit, where the booking-in procedure and contacts with staff were much easier than in the health authority units. The aims of Rivermead were that parents should never be turned away and they should be helped according to their needs. This was sometimes difficult to do, but even the way in which the staff answered the phone ('Rivermead, can I help you?') emphasised their wish to help and gave parents a positive feeling that the organisation was designed to meet family needs. The staff of the three health authority units (Collingwood, Field Lodge and Northbridge), *thought* they gave a family oriented service but they were in fact quite rigid with regard to booking-in and allowing flexible use.

Five parents said they liked the mere existence of short-term care, whether or not they intended to use it very much. 'Just knowing it is there is what helps us', they said.

Did parents think they would continue using short-term care?

Eighty-eight families were asked whether they intended using short-term care regularly over the next few years or if it was only helping them out in a temporary period of need. (Parents whose children were very frail or suffering from deteriorating medical conditions were not asked this sensitive question.) One family did not answer the question. One mother, a 59 year old widow with an adolescent handicapped son, said: 'No, because I'm seeking permanent care somewhere for him'. Eight families said that they were not sure whether they would continue using it, as they really hoped that there would be either an improvement in their children's development, or changes in neighbourhood attitudes which would mean that they no longer had to send away their children for short-term care. One mother said that she definitely did not intend using short-term care for ever, because sending her child away from home was not normal.

> 'I might use it in dribs and drabs, if it suits me to, but normal children do not go somewhere else to live so why should handicapped children?' This mother had a totally dependent four year old daughter and at the time of the interview she was using Rivermead for occasional overnight stays after having had some very unsatisfactory experiences when using hospital wards for short-term care.

Seventy-seven of the 88 parents said they definitely saw themselves continuing to use short-term care on a regular basis in the years ahead. Some described the service as so important to them that they would never move to another district in case such help was not similarly available; one father turned down an offer of promotion in his work as a university researcher because it would have meant moving away from the area and he did not think that there would be such a good short-term care hostel as Rivermead anywhere else.

Even those parents whose children were in their teens and would not be allowed to go to their short-term care facility much longer because it did not take anyone over 16, still saw themselves continuing to use short-term care although they did not know how and where this would be provided. It was sad to note the worries of these old parents, some of whom had been long looking forward to a short-term care facility starting in their districts. But as it had been slow in coming and their children were now in their mid-teens they would only be eligible to use it for a year or 18 months. They expressed great anxiety about the future and some were so fraught by the knowledge that short-term care would finish when their children were 16 that they said they almost wished that they had 'never had a taste of it'. One parent said, 'They offer us this carrot and then promptly take it away'. Parents of profoundly handicapped children had particular worries because they not only faced the end of short-term care when their children reached the age of 16, but the end of school too and the likelihood that they would not have places in social education centres* because they were so gravely handicapped. The parents is one area mentioned at least five profoundly handicapped young people who were in this plight; they had left school and were at home all day and their parents did not have

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* In 1982, the title social education centre replaced the old name of adult training centre.

the relief of short-term care or school. Life for these families had become extremely confined.

Worries about short-term care stopping at 16 did not occur for the parents of children using Field Lodge mental handicap hospital because there they could be transferred to adult wards. These parents spoke with more resignation about the future care of the their children. The advice of professionals and the existence of the mental handicap hospital catering for all ages had apparently persuaded them that long-term hospital care would one day be inevitable, although the hospital was a bizarre and inappropriate place to live. The parents of an active six year old boy with Down's syndrome receiving a week's short-stay care every three months in Field Lodge Hospital children's ward, said that the doctor there had asked them 'When are you going to give up and let us have him in permanently?'. However, although some parents felt resigned to the long-term hospital care because there seemed to be no alternative, they were not necessarily happy about the prospect and some said that they dreaded their children growing up and having to go into adult wards instead of being able to live in houses in the neighbourhood.

Parents' suggestions for improvements

The parents were asked to make suggestions for improving the particular service they were using, (Table 8). Thirty-two of the 101 said that they did not think there was any way in which it could be improved; ten did not answer the question. The suggestions made by the remaining 59 parents reiterated the thread running through all the findings in this study: that is, parents want support and they want short-term care to be readily available, but they have serious reservations regarding the care of their children and their own contact with staff. With 31 parents suggesting improved availability of short-term care there was obviously a strong interest in the service continuing. No matter what reservations they may have had about quality of care, they hoped the service would be expanded to meet the needs of everyone of all ages, either through the building of another unit or through more beds being provided on the site they were currently using. Despite the trend towards developing small locally based units, some parents still had faith in the idea of large facilities providing traditional asylum-type care; if they were using wards on old, rundown hospital sites (ex-fever hospitals or maternity hospitals) they were inclined to think these sites should be renovated and developed to accommodate large groups of mentally handicapped people.

The answers showed surprising little concern for the politics of service provision; for example, the financing and planning of services.

Even those parents who had received higher education and professional training, who might have been expected to have some insight into public services provision, were ill informed about the organisation of services, local government, the differences between health authority and social services responsibilities, compulsory and discretionary powers of provision. Only three parents referred to the financing of services, one suggesting that more money should be provided for mental handicap services, one suggesting that parents should pay something towards their children's keep in the hostel to ensure that it would not be closed because of cut-backs in public spending, one suggesting that foster parents should be paid more for looking after their children.

Only five of the 16 single parents in the study made any suggestions for improvements and only three of these wanted improvements in their children's care. As mentioned on page 91, in the section on parents' dislikes, it seemed that the vulnerability of single parents made them reluctant to point out flaws in their children's physical care.

The 33 parents who suggested that the care of their children should be improved and the nine who wanted better communication between parents and staff, were all using traditional forms of residential care (hospitals and hostels). It was significant that none of the parents using the fostering scheme had any suggestions to make regarding the quality of their children's care or their own communication with the carers. They were very concerned that the service should continue and did not feel that it could provide any better quality of care than it did at present. Their only suggestions for improvement (made by four foster scheme users), were concerned with the availability and financing of services: for example, fostering should be available for the over 16s, foster parents should be paid more, every parent of a handicapped child should be allowed at least one week's short-term fostercare each year.

Only two parents thought that staff needed to be 'better trained to give specialist advice' (for example, therapy, medical, psychological). Contrary to the belief of some professionals that families are eager for advice from 'experts' and want to be in contact with 'a centre of excellence' or 'resource centre', when the majority of parents referred to the care staff needing to be better trained they did not mean in order to offer specialist advice but to have more knowledge about child care and play so that the children would be looked after properly when they were having short-term care.

The details of the suggestions made by the 33 parents regarding the need for improvements in child care standards illustrated their wish for short-term care to be much more child oriented and not merely a separation service. Particular disquiet about the staff, their training and the way in which they organised their time and how these matters affected the children's care, was shown by those parents using the health service facilities. The following remarks reflect the general dissatisfaction that parents felt about the children's care:

> 'It would be much better to have houseparents instead of nurses.'
>
> 'Staff should have a background of teaching, then they would understand the children.'
>
> 'Staff should be employed who understand children's feelings.'
>
> 'It would be better not to use so many volunteers to look after our children.'
>
> 'There should be more play opportunities.'
>
> 'The unit should be more like a children's home.'
>
> 'They should take in children who know each other, in this way they would enjoy their stay better as the group would be friends.'

This last suggestion, made by parents using a health service facility, was actually a practice in the social services hostel (Rivermead) where the care staff and teachers and parents collaborated in seeing that children who were friends could sometimes have short-term care at the same time.

Only one family made a suggestion which was directly against their child's interests: they did not like their seven year old daughter being allowed to play with water at the hostel and they wanted the staff to 'curb play that will teach them how to make a mess at home'. The parents disapproved of their child being encouraged to enjoy lively play activities in the hostel because the family home was above the premises of the firm that employed the father and they thought their livelihood and accommodation would be endangered if the little girl got too excited at home or learnt to turn on taps and flooded the flat. The hostel staff were aware of the tensions within the family but felt that the child should be permitted to join in the free play activities that she so much enjoyed with the other children when she was having short-term care; it was a difficult situation for the staff and parents to resolve.

Only nine parents made *direct* reference to the need for better communications between parents and staff, but in the suggestions made by the 33 who wanted improvements in child care there were indications that deficiencies in care were closely related to poor contact between staff and parents. The care of the children was

Table 8 Parents' suggestions for improving services

Improvements suggested by 59 parents	Number of parents making the suggestion	
Better care of the children: (take fewer children, keep ages together, more supervision, look after their clothing, take children who know each other, introduce the child to the service in a better manner, allow mothers to share the care more, be more like a home)	14	Suggestions concerned with quality of child care
Better staffing: (more staff, houseparents instead of nurses, staff should have teaching experience, staff should be better trained and qualified, employ staff who understand children's feelings)	11	
Better play and activities for children: (more outings and activities, children should be played with more, the most severely handicapped should be helped to play, there should be more toys)	8	
Total directly connected with children's care	33	
Availability of service: (more beds, easier admission in a crisis, more frequent and shorter care to be allowed (maybe just a few hours), easier access in summer holidays, another unit to be built, have a locally based service, accept the over 16s)	31	
Better communication between staff and parents: (staff to be more welcoming, parents to be introduced to staff, parents to be shown where children will sleep, parents to be allowed more involvement in children's care, parents to have more information about services, the children's programmes and routines to be followed according to parents' wishes, parents to be fully informed about all that happens to their child when in short-term care)	9	
Improvements to the physical amenities: (nicer buildings, more security, safer glass, a minibus, a swimming pool)	7	
Better cooperation between professionals: (more liaison between schools and short-term care units, care staff and others (social workers, psychologists, doctors, physiotherapists and speech therapists) to have better contact with each other)	3	
Improved financing of services	3	

intrinsically linked with parent/staff contact; good relationships could help to smooth the way for the children's stays, ensure that their 'little ways' were understood, and give parents confidence through knowing that their wishes and advice had been listened to and appreciated. The degree of the parents' involvement in their children's care via personal contact with staff was crucial. It could make short-term care either a positive experience of sharing their children with other people or a negative experience of loss, lack of communication and strained relationships.

> 'It would be better if they *listened* to parents.'
>
> 'There *ought* to be better communication.'
>
> 'We would like to *know* the staff better.'

It was obvious that the parents wanted to be involved in some way with their children's care. They did not want to merely hand them over and forget them for a few days. Even in Rivermead, the popular social services hostel, there were parents who thought that the service could be improved by more cooperation between parents and staff regarding the children's daily routines.

Summary and conclusions

Short-term care can be a helpful form of support but parents have numerous dislikes about it; they are not always very happy about the way in which their children are looked after and they feel upset about being separated from them. Although parents like the freedom they get by having short-term care they miss their children far more than is generally appreciated by professionals and they sometimes find the freedom very disconcerting.

Their dislikes tend to be related to the type of facility they are using; the care given in mental handicap hospitals provokes most dislike and fostering is most satisfactory. The advantage of fostering is the personal contact that the fostering families develop with the families of the handicapped child.

Professionals are not sufficiently aware of the many dislikes that parents have about short-term care. Parents and staff of facilities do not meet enough to discuss the needs of the children and the problems caused by the separation.

Short-term care is popularly thought to prevent long-term care but, if it is badly provided, it may disturb the children and actually result in them drifting into long-term care.

Short-term care rarely tails off once it has started, it either increases or stabilises. Most parents saw themselves continuing to use it and they were worried about the likelihood of it stopping when their children reached the age of 16.

Parents' suggestions for improving their short-term care services highlighted the need for staff to monitor the quality of child care and to develop much better contact with parents.

Reference

1 Oswin, Maureen. Children living in long-stay hospitals. London, Heinemann Medical, 1978. Spastics International Medical Publications Research Monograph No 5.

5 Parent management in short-term residential care services

Introduction

In the previous chapters, especially those describing families' reactions to short-term care and their opinions of the service, it has been suggested that facilities are not always very satisfactory. The parents met during the study were very concerned about what happened to their children during their stay, the quality of their care, whether they had a nice time or not, if the staff were experienced in looking after children, the need for better contact between staff and parents, and the need for parents to be more involved. Discussions with parents confirmed the suspicions that first prompted this study—that is, short-term care services are too crude and show little respect for the feelings of the parents or the children. The services must be refined if they are going to provide a genuine sharing/caring support system instead of just a separation service.

In Chapters 3 and 4 it was pointed out that parents' initial worries at the idea of short-term care often centred on their own and their children's feelings about the separation and that these worries were not always eased by their experiences. It was also pointed out that, although they appreciated that short-term care was an opportunity for a rest, the parents developed some strong dislikes and anxieties about the ways in which their children were looked after. Their suggestions for improvements illustrated their concern about standards of child care and their wish for more constructive contact with staff. What they said represented the very normal uneasiness that any parents would feel about their child going away from home to be cared for by strangers, irrespective of whether the child is handicapped or not. The *normality* of parents' concern for their absent child is not being sufficiently recognised.

It is plain that parents want more than a separation service, but do they get adequate opportunities to put forward their views to staff and planners? Are they too willing to accept the gap that exists between themselves and the staff, perhaps being reluctant to voice their opinions in case their children are penalised? Do they accept unsuitable services simply because they are ill informed about different and better services being developed in other areas? Is it *possible* to have constructive parent management in short-term care services or is lack of contact between staff and parents inevitable in a service which has grown out of the fundamental idea of separating children from their parents? This chapter considers the question of *parent management.* The word 'management' is used in a very broad sense: that is, involvement of parents in the organisation of child care, their contact with staff, their opportunities to give opinions and influence changes.

What is parent management?

Parent management might be said to exist if parents and staff form an association. However, from what parents said about staff/parent associations it appeared that although the first few meetings may have included discussion about the facility's organisation, the subsequent meetings concentrated on 'safer' topics such as fund-raising activities for a swimming pool or minibus rather than looking at unit aims and policies and how to monitor standards of child care. (See also pages 144–147.)

Parent management might be said to exist if parents are given opportunities to meet all the professionals at the unit who are concerned with their children and to attend their children's case conferences and give their views; but attendance at a case conference may be little more than a token gesture towards parent involvement, the real test is how far the opinions of parents are acted on in direct care of their children.

Parent management might be said to exist if a parent from a local society for mentally handicapped children is invited to attend some of the unit staff meetings, give the views of parents, and report back to the local group and generally act as the representative of parents on the management team of the hostel or ward. But the effectiveness of this will vary, depending on the individual parent and how far he or she represents the views of *all* parents and feels able to comment about the quality of the services.

Sometimes a form of parent management exists because an individual parent starts campaigning for better services and takes on the role of monitoring and criticising local services. He (or she) may then become the spokesman for local parents and his support will be sought and given in any 'fight' with authority. But sometimes these campaigning parents are viewed with suspicion by other parents who fear they will endanger relationships by their abrasive outspokenness and will get all parents labelled as 'bolshy'.

The various ramifications of parent management exist because parents are not clear about their role in influencing policy and monitoring the residential care services they are using. Democracy in deciding the quality of local service provision seems a poor thing. In the National Health Service it is in the hands of community health councils, the statutory 'consumer bodies' which vary considerably in their strengths, weaknesses and interests; and in the local authority it is in the hands of elected councillors who may not be particularly interested in the quality of services. Between 1977 and 1980, the Royal Society for Mentally Handicapped Children and Adults, and the National Development Group, issued checklists on quality of services[1,2], and in 1981 a health circular was issued by the DHSS explaining how to make complaints about care in hospitals.[3] But none of these documents were familiar to the parents who were met during the study. Most parents avoided making even the mildest criticisms to management or care staff and they had little or no idea how to make an official complaint of a serious nature. There seemed to be an unwritten rule that if they accepted short-term care they also accepted without question the 'rules of the house', including the organisation of the staff and children and their own non-involvement in what happened in the facilities.

Care staff and parents often view each other defensively; the staff pay lip service to the idea that 'parents are the experts' but both parties are confused about their respective responsibilities once the children are actually receiving residential care. Parents are puzzled by various organisational issues. Most of them realise that they still have full parental rights over their children when in short-term care but they are not sure how far these rights entitle them to question the quality of the care, especially if the needs of their child seem in conflict with the organisation of staff time or the needs of other children in the unit. They wonder if the staff always know best – they resent staff making changes in their child's routines but do not like to question this. If their child is using a hospital for short-term care, the parents wonder about him being a 'patient'; he is not sick but being in a hospital seems to diminish their responsibility for him, and a note of confidentiality creeps in concerning what happens to him there, which makes them feel that a door has closed on him for the few days that he is away.

Nurses and care staff, many of whom lack experience of working closely with parents, are also confused about their role in looking after other people's children for short periods when they are not ill nor from neglectful homes. This confusion often means that they are fitted into residential care regimes which might have been considered suitable for sick or deprived children earlier in the century but which are not conducive to developing shared care in equal partnership with parents in the 1980s.

Knowing the staff

'I don't worry about his care. I know the staff. Knowing the staff is the secret', said the mother of a five year old, cerebral palsied boy. One of the most disquieting findings of the study showed that this apparently unexceptional remark did, in fact, describe an exceptional situation. Sixty-two parents, using the three main units visited during the study, were asked how many staff they knew by name. Only 18 could name three or more staff, 25 could name two, ten knew one and nine did not know any (see Table 9). The larger the organisation and the more distant it was from the parents' homes, the fewer names they knew of staff who were caring for their children. The three facilities had each started at approximately the same time and the children had been regularly staying in them before their parents were asked the question about knowing staff names.

The parents knowing fewest names were not necessarily those making least use of the facilities. Mr and Mrs Crittle had used Collingwood 43 times for their 15 year old son, but knew the name of only one member of staff; Mrs Green had used Field Lodge Hospital 42 times for her five year old son but did not know the name of any staff. The staff working in Field Lodge, the newly built mental handicap hospital, were least known to parents. Nine of the 17 parents using it did not know the name of any member of the staff who were looking after their children. The hospital was sited behind a district general hospital and in order to reach it the parents had either to cross a busy main road and find their way round the back of all the outbuildings of the main hospital, or cross another main road and

Table 9 Parents knowing staff names

Number of staff names which were known by the 62 parents	Number of the 21 parents knowing staff in Collingwood (NHS)	Number of the 24 parents knowing staff in Rivermead (lassd*)	Number of the 17 parents knowing staff in Field Lodge (NHS)	Totals of the parents and the number of names they knew
0	0	0	9	9 knew 0
1	7	1	2	10 knew 1
2	8	16	1	25 knew 2
3	2	5	2	9 knew 3
4	2	2	2	6 knew 4
5	0	0	1	1 knew 5
6	2	0	0	2 knew 6
	21	24	17	62

* Local authority social services department.

enter the site by walking across a large expanse of waste ground. Such siting obviously did not encourage easy and frequent contact between staff and parents.

In addition to the siting of the units, other causes of staff anonimity were:

a the organisation of staff, especially their movement and hierarchy; and

b attitudes of staff to parents, the way in which initial introductions were made and subsequent contacts.

The movement of staff was a particular problem in the health authority facilities, most of all in Field Lodge mental handicap hospital which was organised as a traditional psychiatric hospital so the nurses were likely to be moved from ward to ward and only the charges nurses and deputy remained permanently. Due to this mobility of staff and the system of working shifts, parents were not likely to see the same member of staff twice in a period of six months or longer, although their children could be using the ward extensively for short-term care. And if the child went to and from the hospital via his school, taken on the school bus, it was possible that the parents would never go to the ward, so even if the staff were willing to make contact they were unlikely to get a chance to do so. (See pages 124–125 and Chapter 6 pages 161–162 and 164–166 for further references to the use of school buses.)

The reason why more parents using the local authority hostel knew staff names might be explained not only by the fact that the hostel was locally based and the staff were permanent, but because the officer-in-charge had made efforts to contact parents during the early months of the hostel's opening. She had organised meetings, visited parents in their homes and attended meetings of the local society for mentally handicapped children. But even with these efforts there were some parents using the hostel who never saw staff because their children were taken to and from on the school buses.

The *position* of the ward or hostel staff known by the parents was significant, the most known being the person in charge and his/her deputy. Hierarchical management of staff could prevent juniors from making good contact with parents, by not allowing them to do the bookings and discouraging them from approaching parents to discuss their children in any but the most superficial manner. Some of the staff who were labelled 'junior' were by no means junior in age or experience in bringing up children, and it seemed a great mistake that they were not encouraged to make personal contact with families. A nursing assistant in her late 40s, the mother of four grown up children, said: 'Sister does not like it if *we* talk to parents about the children, about what they have done, or eaten, or anything like that. She likes to do all that'. This situation was surprisingly common and would result in staff deliberately 'melting away' when parents came because they thought it was the prerogative of senior staff to talk to them.

In the local authority hostel all 24 parents interviewed knew the officer-in-charge and 21 knew the deputy, but only seven knew any other member of staff by name, four of these naming the third-in-charge. So although the hostel had more contact with parents than the health authority facilities, there was still a gap between parents and more junior members of care staff. The tendency of the officer-in-charge to be protective towards the junior members of the care staff acted as a barrier between them and parents, although this had never been intended. It is possible that better contact might have been achieved in the hostel if the junior members of the care staff had had opportunities to visit families; they had expressed a wish to make home visits, but the officer-in-charge had disagreed because she believed that the role of care staff could not extend outside the hostel without affecting the quality of care given to the children.

One reason why parents do not know staff well is because there is little contact between them during their initial introduction to the facility and during the subsequent episodes of handing over their children. Even if the parents' initial introduction is done with sensitivity and apparent success (that is, with one or two prior visits, leaving the child for a few hours to start with, seeing his bedroom, being introduced to senior staff, having coffee in the office and filling in forms about their child's abilities, likes and dislikes), the actual moment of handing over their child for the first period of short-term care can be a serious failure in staff/parent contact. This important moment is often bungled, the parents perhaps not seeing the people they had met on the first visit, not being introduced by name to the staff on duty, not being helped through the distress of handing over their child, not being clear whether he will be looked after by one particular person to whom they also may relate. Distress at this particular moment—embarrassment, shyness of each other, the hurried departure of parents which is often encouraged by staff for fear that the child will make a scene, avoidance of eye contact for fear of disclosing feelings of stress and inability to conceal these, the painful feelings of young staff at seeing parents getting upset, the child's tears – all, or any, of these happenings during the handing over of the child will reduce the chances of secure relationships being built up between staff and parents. Names of staff given at such moments are likely to be quickly forgotten, perhaps not even heard. This situation may recur repeatedly, on the child's subsequent admissions, with parents being faced with different staff on every occasion.

It might be thought that it is up to the parents to *ask* names, but it would seem important for all levels of staff to appreciate that when parents are in a vulnerable and distressing situation they may not find it easy to ask questions. Therefore it is the prime responsibility of the staff to provide information about the unit, and this includes giving their own names. Very young staff will probably lack confidence in coping with parents' distress, and will therefore need the support of senior staff and opportunities to discuss the problem of staff meetings and through inservice training courses.

The aims of short-term care need to be clearly defined for the care staff. It should be made clear that it is far more than merely separating the child from the family so as to give the parents a break. Aims include the building up of parents' confidence in services so that their use of the facility becomes a positive experience built on developing a good relationship with the staff who are sharing with them the care of their children. A secure relationship between parents and staff is an essential part of the whole service, therefore it is vital that the staff are known by their names. As names are likely to be forgotten on the first few occasions that the parents go to the unit, the staff should reintroduce themselves each time; and wearing name tags might be encouraged as a prevention of anonymity instead of being discarded as an old-fashioned formality.

Ironically, anonymity can often occur because staff are trying hard to be informal and friendly, so they behave and dress in a very casual manner. No longer using titles such as Sister, Miss, Mrs, Mr, they seem to be just a confusing, anonymous crowd of casually dressed young people. Many of the parents who were asked who they knew in the units could only make vague references to physical appearances such as 'the very thin one', 'the one with the ginger beard', 'the one who wears rimless glasses and torn jeans', 'the one with blond plaits', 'the one we thought was a girl and then found out that he was a man'. Names, if heard at all, are very short and similar—'Mick', 'Mike', 'Jim', 'Lyn'—or of a unisex nature—which makes the young people even more anonymous—'Kim', 'Kit', 'Jo', 'Jez', 'Chris'.

Parents need to see *evidence of ability* in the people who are going to look after their children. In the early stages of using a residential care facility, a title and uniform may be very important to some parents. A person recognised as qualified by a uniform, title, badge, a name tag, some tangible sign of rank and ability, can ease their doubts about giving their children to other people to look after. With uniforms and titles having been, in recent years, quite rightfully discarded as out-dated trappings which are totally unnecessary in child care services, it is all the more important for staff to make real efforts to develop friendly personal contact with parents; otherwise the discarding of uniforms and titles is not progressive at all but merely creating a new type of anonymity. Wearing similar clothing and bearing similar, easily forgotten, names the staff not only lack official identity but may also appear to be inefficient. The modern and anonymous uniformity of the too casual appearance does little to inspire confidence, no matter how well-qualified and experienced the staff may be: 'It is a bit worrying that they are just long-haired young people all wearing jeans. I think they are students or volunteers', said one mother when describing some exceptionally well-qualified, young staff who had never introduced themselves to her.

It seemed that particular expectations were connected with particular settings. Some parents using hospital units expected formal clothing and titles and were worried when they did not see them.

> 'I do not like young staff who lounge about all casual. There are too many young staff, not at all the people you expect to be looking after your children. I think they are volunteers.' (Mother referring to nurses not wearing uniforms in a hospital.)

Most parents approved of nurses coming out of uniforms, but some like the one above, saw uniforms as evidence of responsibility in looking after their child. Another mother said that she would like the staff to start wearing uniforms again. 'I could see who they were then, and anyway, my daughter likes uniforms' she said. Her request reflected her sense of insecurity at giving her daughter to very young and apparently unqualified people whose names she did not know and ranks she did not understand.

If the parents' expectations of the staff's ability to look after children are upset by a casual appearance, it is obvious that they will be anxious about their child's care. Therefore it would be helpful if they were given explanations, either verbally or in a leaflet, about staff qualifications and experience, the reasons why uniforms are no longer worn, and the aims of the unit in trying to be homelike and informal.

In one health authority unit the staff told me that each child had been assigned a nurse who would be in personal charge of him, to write his records, see to his clothes, have him in a group to play with, 'to be generally the child's friend' they said. It was easy to understand that this arrangement was sometimes difficult to honour because of duty shifts and the movements of the children in and out of the unit; for example, a child might have short-term care on five weekends a year and his assigned member of staff could be off duty for three of those five weekends. It was *not* easy to understand why only two of the 31 parents interviewed from that unit knew about the arrangement and knew the name of the nurse who had been assigned to look after their child. The other 29 parents said that they knew nothing at all about the arrangement but thought it would be a good idea. It was disquieting to know that parents had apparently not been told about the assignment, or , if they had, the implications of it had not been understood. They should have been informed verbally and in writing and introduced to the assigned person; as repeatedly noted in this study, the *parents' perceptions* of the service they received were likely to differ considerably from the *staff's perceptions* of what they were offering. There is a need for staff to constantly reassess and monitor their aims and actions; if not, there is a danger that ideas which sound good on paper might never exist *except* on paper.

As referred to on pages 119–120, regular and frequent use of a facility does not necessarily mean closer contact between parents and staff. There could be no contact at all if the children went to and from the unit via school. This is a very common arrangement. The school bus will pick up a child from home on a Monday morning, plus his case, and after school that afternoon it will take him to the short-term care facility where he will stay for the rest of the week, going to school from there each morning on the school bus, which then returns him home on Friday afternoon straight from school as usual. Or he may go on the school bus to the short-term care unit on a Friday afternoon straight from school and have the weekend there and return home on the school bus after school on the Monday afternoon. Approximately half the families met during the research let their children go to and from the short-term care units via these arrangements with school transport and they rarely took them to the units themselves or picked them up.

Transporting the children to and from their short-term care facilities on school buses is considered a good way of saving parents the task of getting them there, especially if they have not got their own cars. It is also thought good because it saves parents the painful upset of having to take their children themselves and perhaps see them crying when left. It is also said to be 'nicer' for the children to go to and from the units in the school buses when perhaps a small group from the same class may be going in together.

However, there are many drawbacks in using school transport. It can mean that children may have short-term care regularly for a year or longer but their parents will never go to the units. Some parents using this means of getting their children to and from short-term care had *never* been back to the units since their first introductory visit more than a year earlier, and they had never had another opportunity to meet the staff and find out about the development of the unit. It is possible that within a year, most of the original staff in any unit will have left and the early philosophy of the place will have changed and the care have deteriorated considerably, but the parents will continue to believe that the facility is good simply on the strength of their one, introductory, visit. They will be totally unaware of any changes in the care, and their children may not be able to tell them anything. And if regular short-term care periods have been booked for a year in advance, the parents may not even be in contact with the care staff through telephone calls to do bookings.

A classic example of what can happen when a child goes in and out of short-term care on the school bus was noted as follows:

> Mrs Green, the 22 year old mother of five year old Jonathan, always sent him in to Field Lodge mental hospital on the school transport. She said he did not take a case with him as everything—clothes and even a toothbrush and toys—were supplied by the ward. She did not know anybody on the staff. 'I've never been there for months, so I don't know anybody there now. I don't need to telephone to book him in, that's all done by the community nurse for months in advance and I get given a list of the dates he'll be taken in.'

Using school transport to get children in and out of short-term care is not only undesirable because it prevents the parents and staff from meeting each other, it also overlooks the children's feelings about going away, and ducks the issue of how the separation experience may be affecting them. In fact, it very effectively prevents parents and staff from having to face what the separation means to the children. (See also pages 120, 161–162 and 164–166.) For the children's sake it is very important for their parents to take them in and pick them up as often as possible. Those without cars might be helped to do this by the use of voluntary drivers taking the parents and children together to the units.

Contact between parents and care staff could be improved if care staff visited families, but social workers and community mental handicap nurses generally feel it is their prerogative to do home visits. Social workers have, rightly or wrongly, been responsible for creating the idea that family visiting is a highly specialised skill and that it is 'dangerous' for residential care staff to make more than superficial contact with parents. And community nurses, although a much newer profession than social workers, appear to be following social work tradition in claiming special skills in family visiting. Is it possible that these skills are exaggerated to the point of preventing good contact between parents and the care staff who are daily looking after the children? It is a pity if this is so, because when families are learning to use and accept a residential facility, it is essential that they should build up a trusting relationship with the care staff. Contact between care staff and families should never be seen as interference with the casework skills of other professionals, but as an addition to them.

It would seem that social workers, although unable to fully meet their own commitments to visit parents of handicapped children (many parents complained that they had not seen a social worker for months) are reluctant for other professionals to do so. The reaction of one senior social worker to a suggestion that care staff should make home visits was: 'They would need to be specially trained, they could do such damage, they might say anything, do anything, and then there is the question of confidentiality as well'. However, it seems a contradiction of advice if on the one hand social workers are urging parents to use short-term care and hand over their children to other people to look after, and then on the other hand suggesting that these people are not responsible enough to see the parents in their own homes and discuss their children with them. Staff who are considered mature enough to take on the very responsible task of caring for other people's children should also be considered capable of visiting the families without causing 'damage'. From discussions with the parents met during this study, it was plain that they would welcome opportunities for more contact with care staff, and the majority did not need skilled casework but regular friendly contact with staff who were sharing their children's care.

In none of the main facilities concentrated on during the study was there any system of care staff seeing families at home, but in some of the other units which were very briefly visited there were examples of home visiting by care staff. For example, in one health authority unit the nurses took turns to escort children to and from their homes, and in this way they met parents who were unable to make regular trips to the unit and they had an opportunity to discuss the children's stay and hear if the parents had any worries about it. In another health authority unit some members of ward staff were assigned to visit particular families for the purpose of discussing the daily care of the children. For one family these visits enabled them to plan with the nurses a method of helping their child to communicate; for another it meant that a misunderstanding about lost clothing was amicably settled.

The contact made between parents and care staff in the above two places was never intended to supercede the relationships between social workers and parents. The value of the visits lay in mutual discussion about the daily care of the children, a subject about which many social workers lacked knowledge and interest.

Parents look for evidence that their children are known and respected as individuals in the short-term care unit they are using. A few special words on their arrival, such as, 'Have you brought Paddington

Bear again?', or 'Come and see those pictures you liked, they are still above your bed', reassure parents that using short-term care is not merely kennelling their children. They want to see their children greeted by name: 'People always come up as soon as we arrive and take his hands and say "Hello Paul".' They want to know that their children are welcome: 'Nobody grumbles at the children or seems to think they are a nuisance, whatever they do. If anything happens—something gets broken—the staff are calm, in charge but never grumpy, always kind'.

It is important for staff to be not only friendly and welcoming when parents arrive with their child, but also find time to talk to them when they pick him up again. 'The staff are friendly and we mingle, you can talk to them about what the children have done and how they've been in their stay, they are never too busy to stop and talk'.

Parents notice if staff are moody according to who is on duty. 'Sometimes when we have been up there it has seemed OK but at other times it is completely different and there's a set of staff on duty who ignore us and are quite rude really'.

Some parents who had been using short-term care very regularly said they *always* felt unwelcome. Fleeting expressions of impatience or boredom on staff faces, inflexions of voice in face-to-face contact or on the telephone, and obvious disinterested responses to parents' questions were seen as signs of unfriendliness. The staff, however, may have explained their behaviour as not intentionally unkind but just caused by pressure of work.

> 'We are not encouraged to stay. I'd like to be more part of the place but this is not encouraged at all. I'd like to be able to go in and put out his Teddy on the bed, but I can't do this. We'd like to know more about things, what happens there, but the staff don't seem to want parents around and they never share information. My mother-in-law heard at her office about how some little Girl Guides go up there and work in the wards every Saturday afternoon, and this lady who was talking to her didn't know my mum-in-law had a handicapped grandchild in the ward sometimes, and she was going on about her daughter who is a Girl Guide and how she feeds the spastic children by tipping their heads back and pouring the food in, and my mum-in-law was horrified and came and told me and I thought I wonder if they do that to Quentin. Nobody had ever told us that little girl volunteers would be looking after him and feeding him. The nurses don't want parents there, yet they let young volunteers in, they could choke him.' (Mrs Rowland, the mother of nine year old Quentin, a very dependent, multiply handicapped boy.)

> 'The staff should be more forthcoming. I feel a nuisance if I ask about anything. We went up there one day to fetch him and I asked about the plastic container we sent in with him, and they seemed to think I was queer to ask about things like that. The staff always seem so busy and harrassed, too busy to bother with parents and they make us feel a nuisance. They don't want to know what he does at home and how we play with him or anything.' (Mrs Taylor, the mother of a six year old, severely handicapped boy called Maurice.)

> 'I walked in one day and they were grumbling at her, telling her off properly and I said to them "Leave her alone, I'm her mother".' (Mrs North, mother of 15 year old Diane.)

The sad point of Mrs North's story was not so much that she was upset to find her daughter being 'told off' but that there had never been any contact between her and the staff, so when she walked into the unit unexpectedly and saw her child being chastised she had to first identify herself ('I'm her mother') and start from a position of defence.

The gap between parents and staff was vividly illustrated one afternoon in a mental handicap hospital ward when I suggested to the staff that a mother should be invited to come and show them how she coped with her little boy; he was in for short-term care and the staff found him very difficult to feed. They replied, 'Good heavens, if we did that she might think we were keen to have him and she might then send him in more often—we don't want that to happen'.

The lack of contact between families and staff was a worrying feature of all the facilities visited. If one looks at short-term care in the same terms as bringing up a normal child, it seems very shocking for parents not to know the names of the people who will be caring for their children. If normal children go to stay with somebody for the night, the parents *always* know who will be putting them to bed—an aunty, a grandparent, a neighbour—but it seems as if all the norms of child care are turned upside down for handicapped children so that it is accepted as a good idea for their parents to regularly send them away to stay with unknown people.

Developing Trust

If short-term care is ever going to succeed, it is essential for parents and care staff to have a trusting relationship. Trust includes honesty about the children's reactions to their stay. Honesty is evidence of respect for parents' feelings. They do not want protecting from what they suspect, that is, that their children have been upset, or have been homesick. Indeed, they find such protection irritating and patronising. They also suspect that if staff are not frank with them about how their children react to the separation, then they may also cover up for other matters connected with their stay.

> 'We can trust the staff, they tell us the truth.' (Parents of a four year old, multiply handicapped child.)
>
> 'They are always honest with me about how she's been.' (Mother of a four year old, cerebral palsied child.)
>
> 'I like their honesty, they don't just say she's been settled, and tell lies; if she's cried all night they tell me so, they always tell the truth.' (Mother of a four year old, multiply handicapped child.)

The above three families were using Rivermead, the local authority hostel, where, if the children were going home via school instead of their parents coming to fetch them, the staff always put a little note in their cases describing what they had done during their stay, their play, their food and outings. This was a means of maintaining contact if the parents were unable to fetch their children and see staff. However, although the note idea is good, it is still important for parents to try and visit the units as often as possible, for, as discussed earlier (pages 124–125), places can change over the months and the parents need to be aware of any changes in the staff, and the organisation of care, and not just go on blithely thinking that the units they saw and felt happy about six, nine or 12 months ago are still exactly the same.

The staff of the health authority units seemed to have particular difficulties in developing and maintaining trusting links with parents. 'The staff don't tell us about things enough or say what he's done when he's there', said the father of a 14 year old boy using a health authority unit. This was a common criticism of hospitals being used for short-term care.

In some instances the parents would ask about their children's stay in a health authority unit and be politely put off with such remarks as: 'I was not on duty' or, 'I've only just come on duty, you must ask Sister, she'll be here next week' or, 'There's nothing in the record book to say he's not been OK'. A child's anonymity in a large organisation is confirmed by such remote reponses to a parent's queries. Sometimes there was a gross failure to convey important information about a child's stay, so gross as to indicate an almost brutal disregard for parents' feelings and rights, as the following three stories show:

> Fourteen year old Kevin Morrison was regularly using a health authority short-term care unit, but his parents rarely visited it and

did not know the staff. One day when he returned home after a week's stay, his parents were upset to see that his hair had been cut very short. They had not been asked whether they wanted his hair cut and there was no note to explain why it had been done. His parents said they were 'furious' but did not like to say or do anything about it.

Fourteen year old Eric Netherton was very severely mentally handicapped and unable to speak. He was regularly using a health authority unit. His parents occasionally visited it, taking him there and bringing him back, and they thought that they knew the staff quite well. One day he returned home from the unit via school, as he sometimes did, and seemed particularly upset. As he was unable to speak he could not explain what was wrong, but he kept pointing to his leg and making a 'needle sign' (pointing and jabbing with his finger, a sign he used in reference to having an injection—he had learnt this when he went to the dentist with his mother about a year before). His parents were puzzled about why he should be making his 'needle sign' after having short-term care so they telephoned the unit and asked what had been happening there. They were then told that he had had 'an outburst of temper' during his stay and had been given an injection to 'quieten him down'. His parents were justifiably very angry about this and said: 'The staff should have telephoned us and told us he was difficult and then we would have gone over and fetched him back. They had no right to give him an injection without asking us. And they never phoned or sent a note. We would never have known at all if Eric had not tried to tell us himself what had happened to him'. His mother said that the next time he had gone to the unit he had been reluctant to go in the door and had seemed upset at being left.

Five year old Jenny Baker was severely mentally handicapped and described as 'autistic'. She had severe behaviour problems, being over-active and occasionally abusing herself by slapping her face. She regularly had short-term care in a health authority unit. Her parents occasionally went to the unit but felt that they did not know the staff well. Every time they went they seemed to see different people on duty. One day Jenny arrived back from the unit and had a bottle of medicine in her case. Her parents wondered what this was for so they telephoned the unit and were told that she had been seen by the doctor during her stay as she had seemed more disturbed than usual, and he had prescribed some medicine for her. Her parents were cross about the lack of communication, feeling that the staff should have telephoned them and explained that she seemed more

> upset and that they were getting the doctor to her. Another day Jenny arrived home and her parents were horrified to find that her arms were confined in 'squeezy bottles' with their tops cut off, so they made long confining arm-bands preventing her from bending her elbows. The parents phoned the unit to find out why these restraints had been placed on their daughter's arms, and they were told that this was a way to prevent her from slapping her face. These two instances of gross lack of communication upset Jenny's parents, but they continued to use the unit and said little about their feelings of anger and disquiet because they did not want to upset the staff or prejudice them against their child.

The problems of poor relationships between parents and staff are very often rooted in the casual manner in which initial contacts with unit staff are organised. Initial contacts are generally organised haphazardly, depending on what is most convenient to a particular professional at a particular time. For example, a social worker might introduce one mother because it conveniently fits the day's caseload to bring her into the unit at a certain time, another parent might come with a teacher, another might make initial contact at a parents' meeting attended by the officer-in-charge. Explanations about the unit's organisation might be given by a teacher, a social worker, health visitor, community nurse, a family doctor or the direct care staff. Information is sometimes out-of-date, repeated, contradicted or incomplete. Sometimes it is given in writing via a letter or a leaflet about the unit, sometimes just verbally over the telephone.

Not all short-term care facilities have information leaflets for parents. And the leaflets that do exist vary widely in their quality of production and content. Some state what they have to offer in clear and simple terms, but others are badly written and contain fuzzy clichés and pompous statements which are virtually meaningless. The people who write the leaflets sometimes seem confused about whether they are writing for parents or newly qualified professionals or a planning committee, so the final result often reads like a mixture of an area plan and an inservice training lecture about community care. It would seem most important for every facility to have a carefully written leaflet which is interesting and informative; and it should appeal to parents from differing backgrounds, some of whom may have problems of literacy and language, whilst others may be very articulate. The example shown overleaf illustrates the poor quality of some of the leaflets being handed out to parents.

This example epitomises the mixture of pomposity and patronage so prevalent in short-term care facility leaflets when the writers lose sight of the essential normality of child care. They refer to staff eating

BROOKHILL SHORT-TERM CARE UNIT

Blanktown, in Whiteshire

OUR AIM IS TO PROVIDE SHORT-TERM CARE FOR MENTALLY HANDICAPPED CHILDREN FOR COMPREHENSIVE ASSESSMENT, TO ALLOW SPECIFIC THERAPY PROGRAMMES TO BE CARRIED OUT OR TO ALLOW FAMILIES TO HAVE A BREAK.

CONSULTANT PSYCHIATRISTS: DOCTOR JONES
DOCTOR BLACK
DOCTOR SMITH

STAFFING: Clinical responsibility is in the control of a Consultant. The unit is under the general management and control of a Nursing Officer. In addition to this, care staff of various grades are in post. The staff have received an intensive period of formal training in the care of the mentally handicapped and of children, and regular inservice training will be continued.

DESIGN: Home-like conditions are prevalent in the design. The bedrooms contain one, two or three beds and are furnished with wardrobes and shelves for each child's individual clothes and possessions.

EDUCATION AND TRAINING: The majority of the children will attend Woodlands School. Individual training programmes will be in operation out of school hours and regular meetings of Care Staff and other involved disciplines are held in order to ensure continuity of care. Parents are encouraged to discuss any aspects of their child's care and training with the Nursing Officer.

MEALTIMES: These times are an important part of any family day. Staff eat their meals with the children in order to teach correct behaviour and encourage conversation.

VOLUNTARY HELP: Anyone interested in giving help is encouraged to contact the nursing officer. Voluntary help and interest is always welcomed by the staff.

OTHER ACTIVITIES: The children will be taken into the Community as often as possible, for example, shopping expeditions, outings to local parks and beaches, cinemas and swimming. These activities are not only recreational but are an important part of social training.

with children and bedrooms furnished with wardrobes and 'expeditions' to 'the Community', as if children with mental handicaps are entirely different from other children and are being suddenly introduced to normal everyday things for the first time in their lives. And in referring to 'various grades' of staff being 'in post' and various 'disciplines of staff' and 'inservice training' and 'clinical responsibility' they fall into the trap of using fatuous professional jargon and clichés which can add nothing to the parents' knowledge of a facility. Such leaflets reveal a certain naivety amongst the staff who write them, some of whom have spent years working in mental handicap hospitals and find it difficult to throw off the old habits of institutional thinking, so the fact that a child has a wardrobe of his own and is taken shopping seems to be unusual and exciting and part of a 'programme' rather than just an ordinary childhood happening.

The simple wording of a leaflet produced by Croydon social services department (part of which is reproduced on page 135) referring to the needs of the children and parents and giving a few items of useful information was a refreshing contrast to the heavy jargon of Brookhill and others collected during the study.

As mentioned on page 131, haphazard arrangements for initial introductions are likely to set the scene for continuous poor contact between parents and care staff. In none of the units visited was there any one professional accountable for seeing that parents would be helped to develop good relationships with staff and given information about the facility. One father, overwhelmed by the conflicting information that he had been given said 'What we want is a book of rules'.

The following mother's introduction to a health authority unit illustrates how ill-prepared some parents may be when they are starting to use a residential care service for their children:

> Mrs Isaacs arrived at the unit during Saturday afternoon. We (the staff and myself) were sitting in the garden. Some of the children were playing in the paddling-pool, others were lying on blankets. Mrs Isaacs brought two year old Anne over to us and sat down on a blanket. It was her first visit to the unit and she was going to leave Anne there for the weekend. This had been arranged by her social worker. She had received no preparation for her child's stay. She asked if she could leave Anne's own clothes or would she have to wear the unit clothes. I took her to see the staff nurse who explained that it would be better if she took Anne's clothes away with her when she went if they were not marked with her name. The little girl was undressed and put into the unit clothes. Mrs Isaacs rolled up the clothes she had arrived in and put them into a shopping bag to take

> home. I asked her if she had received a note explaining the organisation, the need to mark clothes, whether she could stay for a while with her child, whether she should make a few short visits before leaving her overnight. But she said she had received no information at all. (Extract from study observations 1979)

Mrs Isaacs continued to use the unit, and during an interview with her a year later, she said that she did not know the staff and did not know whether any one person was assigned to Anne. When she took her there she would either give her to the first member of staff she could see or put her down in the dayroom. She did not linger in case the little girl started to cry or wanted to be picked up and cling. Nobody had ever encouraged her to stay for a while. When asked about Anne's reaction to her stay Mrs Isaacs said, 'She seems a bit strange when she comes home, keeps staring about the room'. Asked what she liked about using short-term care, Mrs Isaacs said it gave her 'freedom from Anne, the chance for a lie-in and a chance to get out in the afternoons. I want the chance to be a normal woman again as well as a mother, and short-term care gives me that chance'.

It could not be said that there were bad relationships between the Isaacs family and the care staff, there was just no contact at all. Nobody had ever suggested to Mrs Isaacs that short-term care could be a *sharing of Anne's care* and that she herself should be involved. Nobody had suggested that it would have been a good idea for her to introduce the little girl to the unit slowly and to stay with her, perhaps leaving her for only a few hours at first before she ever left her for an overnight stay. Nobody had given her preliminary advice on signs of homesickness or about the importance of letting Anne wear her own clothes when she was away from home. Were the care staff at fault, or the social worker who advised the residential care and made the initial arrangements? And who was responsible for the *continuing* lack of communication between Anne's parents and the care staff? It certainly seemed remiss that the social worker was not following up the outcome of her earlier advice, checking on the effects of the separation on Anne, and assessing whether the little girl really needed to have short-term care and seeking information about the parent/staff contact.

The above questions and the story of Anne Isaacs, and the lack of communication between her parents and the care staff, point to key issues in providing short-term care, one of the most important being *the decision to take a two year old child into residential care.* Mrs Isaacs said that she liked using short-term care because it gave her freedom from Anne and 'the chance to be a normal woman again instead of just a mother'. Was freedom needed because the little girl's

SHORT STAY CARE FOR MENTALLY HANDICAPPED CHILDREN*

This leaflet tells you about short stay care facilities for any mentally handicapped child at a special school and who lives in Croydon or whose family live in Croydon.

The facilities are there to provide more than just a once-a-year break in the summer holidays—they are there also to provide short breaks (from a few hours to a few days) frequently throughout the year; for example

—to go shopping alone
—to go out for an evening
—to take your other children out for the day
—to just be at home alone with your other children
—to go away for weekend or any other reason at all.

The service is free but during longer stays the Attendance Allowance may not be payable. At the moment there is no time limit to the amount of short stay care each child can receive, although it is not normally possible to provide more than 2 weeks at a time.

CARING FAMILIES

There is a pool of 'Caring Families' who have each expressed an interest in looking after a mentally handicapped child. Each of the Caring Families has been through a vetting procedure and a preparation programme run by parents of mentally handicapped children. The aim of the scheme is to link the family of a mentally handicapped child with a Caring Family. In this way you, his parents, can have regular breaks and your child can spend short periods with the Caring Family, just as his other brothers and sisters may visit their friends homes.

FURTHER INFORMATION

Peter Elfer 686 4433

CALLEY DOWN

'Calley Down' is a house in Calleydown Crescent in New Addington with five members of staff under the leadership of Mrs xxxxxxx. Between 4 and 6 mentally handicapped children can stay at any one time and the intention is that as children gradually get to know Mrs xxxxxx and the staff, they can spend frequent short stays there, eg, in the evening, overnight, at weekends or longer.

INTRODUCTORY VISITS

We regard it as essential that children have the opportunity to get to know the people who will be looking after him or her. Introductory visits are therefore always arranged at Calleydown or to a Caring Family.

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* Reproduced by kind permission of Croydon Social Services Department (1984).

handicap brought very special problems from which Mrs Isaacs required genuine rest, or was her tiredness the normal tiredness experienced by most young parents of two year olds who often feel the need to have a lie-in, to shop alone, to be 'free'? As referred to elsewhere in this report, children with handicaps are at risk of having decisions taken about them which would never be taken for normal children. (See also pages 68–70 and pages 75–76). Mrs Isaacs was a caring mother, but very young with no experience of bringing up children as Anne was her first child. On the advice of her social worker she had been drawn into using a residential care service, and was continuing to use it without ever considering its likely effects on Anne and her own relationship with her child, or questioning whether she and her husband really needed this form of support anyway.

There is a risk that some professionals will always recommend residential care for handicapped children because they have an exaggerated view of them being burdens, which obscures their recognition that all young children, not only handicapped ones, restrict their mothers' freedom. From my meetings with parents and professionals, there was little evidence to show that professionals were trying to sort out whether some mothers' problems were specifically related to their children's handicaps, or whether they were the problems common to any women faced for the first time with the restrictions caused by being a mother and, like Mrs Isaacs, wanting to be 'free' again.

It is possible that some professionals will bring to the family situation their own and society's prejudices about handicapped children, and they will blame the handicapped child for any normal stress that is occurring in the family and recommend that they should have short-term residential care when such advice would never be given for a non-handicapped child. In fact, a major criticism of short-term care is that it can promote thoughtless separation experiences for young handicapped children because too many professionals start off from the assumption that all handicapped children are a burden to their families, and they do not give sufficient consideration to their needs as children.

One of the recommendations to come out of this report is that professionals should beware of setting up what I describe as *separation services* founded on the assumption that all handicapped children are a burden to their families. They should always consider whether the families' problems are being caused by the normal strains of young parenthood, or by the peculiar difficulties of the child's handicap or (as pointed out on page 28 and page 31), by social problems. And they should have the courage to point out, if necessary, that it is not always in the child's best interests to go away from home and that the stress the parents feel is not so much due to their child being handicapped but to either the normal problems of being young parents or to social problems which might be eased through better housing or higher wages.

If the social worker and the staff of Mrs Isaac's unit had been more in tune with the necessity for parents to be involved in decisions about their children's care, she might have had the opportunity to discuss Anne's needs, as well as her own, and plan the best way of meeting those needs. This might have resulted in her not using the unit at all but having a more appropriate and child-oriented form of support, such as the help of a baby-sitting service or a link family where Anne could have had an occasional afternoon or overnight stay instead of going into a large and impersonal residential unit. Parent management and the development of trust means staff and families planning together and looking at the child's needs as a child instead of the parents being encouraged to have a blind faith in the advice of professionals and a blind acceptance that separation from their handicapped child is always desirable.

Parents who had been well prepared for their child's short-term care, by having several preliminary visits and opportunities to meet the staff and stay for a few hours before they finally left their child for a night's stay, said they found these slow introductions very helpful. They prevented them feeling cut-off from their children and the staff who were caring for them. Sometimes, however, in spite of careful introductions the staff missed valuable opportunities for *continuing* good relationships with parents. The following observations, made during the study, illustrate how a group of staff working in a health authority facility did not take advantage of an excellent chance to develop good relationships with a family.

> Six year old Ruth Stevens is having her first stay in the unit. She has come in for two weeks because her mother is having an operation. As her mother's operation had been booked well ahead, it was possible for her parents to prepare her quite carefully for the impending separation. She has paid several day visits to the unit with her mother and has been given reassuring explanations about why she is going to stay here. And before she came in she was taken to see her mother in the hospital. The parents, grandparents and older sisters seem to have done all they could to ease any worries that Ruth might have had about her stay.
>
> However, the family's efforts to ease Ruth's worries about the separation have not been well supported by the unit staff. They showed some interest in the preliminary visits made by the little girl and her mother, but since she came in they have shown no en-

> thusiasm for contact with the father when he visits. He comes in every evening for a couple of hours.
>
> Nobody has been particularly unfriendly, but there is a certain coldness towards the father and nobody seems interested in having a discussion with him about Ruth and her stay. Mr Stevens is anxious to be reassured that he and his wife have arranged Ruth's care in the proper way, and he definitely seems to be in need of some friendly chats. When he visits he frequently says to me: 'We thought we would explain it all to her but we are not really sure whether we have done the right thing or not'. He wonders whether it is right for him to visit her every evening and he is worried about the separation experience having some later effects on Ruth and seems very anxious to talk about all this with somebody.
>
> It would seem essential, and also kind, for the staff to find time to talk to Mr Stevens when he visits Ruth, and give him a chance to air his worries and get reassurance. He is a very thoughtful, anxious and caring father, but nobody on the unit staff seems to want to sit down with him and talk about Ruth.
>
> The staff have very negative attitudes to Ruth. They think that she is too active and interfering. Today the deputy charge nurse described her as 'just a spoilt brat. She gets her own way all the time at home'. The staff reaction to the father visiting every evening and his attention to Ruth is a mixture of disinterest, cynicism and criticism about what they feel is his 'spoiling'.
>
> Ruth loves her father's visits. She pulls him by the hand up and down the corridor, showing him her room, and he patiently follows her and can be heard saying: 'This is your nice bed then?' and 'Here's dolly'. This evening when she rushed into the clinic room and grabbed a box of beakers he carefully explained to her what they were used for and why she could not have them, showing her how to put them back into the box and using simple words to explain it all.
>
> His very patient and loving ways with his child and the way he is always helping her to learn are not respected and valued by the staff. They seem to resent his attention to her. (Extract from study observations 1979)

Some parents judged good contact with care staff in terms of how much the staff would cooperate with them in following out the programmes of training that the children were doing at home. The following story illustrates a common dilemma in residential facilities.

> The mother of four year old Andrew East devised a programme to help him to communicate. He was said to be autistic. The

> programme was very sensible and consisted of him being given careful verbal explanations about what was happening all around and what he was doing. His mother was very anxious that his programme would be kept up when he was having short-term care and she did not want him to be left on his own for too long without any verbal explanations. The care staff did their best to cooperate with Mrs East's programme for Andrew, but they sometimes found it difficult to give him the attention required because they had twenty other children always in the unit.

It is understandable that parents want their children's programmes maintained when they are away from home, but when a facility has been planned to provide short-term care for large numbers of children—ten, 15 or 20—it is very difficult, and may even be impossible, for the staff to follow out an individual programme.

How far the staff are able to do as parents wish will not only depend on how many other children are in the unit at the same time, but also on staff understanding of a programme and their sympathy with it. It was easy for the staff to understand Mrs East's instructions about Andrew, for they were merely required to make efforts to talk to him in very simple language. But they sometimes get puzzled about programmes which have been devised by teachers and psychologists and given to the parents to do at home with the expectation that they will also be kept up to date by the care staff when the child goes away for short-term care; they may be based on behaviour modification principles and require careful observations and written records. Some programmes may be in direct conflict with the views of care staff, teachers, psychologists and other professionals, such as the Doman 'patterning' which parents sometimes follow after visits to America.

If children are on individual programmes devised by their teachers, psychologists or parents, it is essential that these should be discussed with the staff before the short-term care is started; but it so often happens that nothing is said to warn either the parents or the staff that a programme is likely to cause conflict until the child is actually in the unit and the problems of how, or why, the programme should be adhered to are already occurring.

Sometimes there were instances of care staff putting children on 'training programmes', such as how to feed themselves or hold a cup, without consulting the parents. Full consultation is necessary, not only to avoid the likelihood of confusing the children and contradicting work already being done by parents and other professionals, but because parents have a right to be kept fully informed of all decisions taken about their children, however unimportant these may seem to the care staff.

Parents usually fill in forms about their children before they go in for short-term care (see also page 56). Some forms ask for information about the children's likes and dislikes, behaviour at home and how they communicate. All have questions about incontinence and mobility, these apparently being considered highly important. The forms are not always very helpful in conveying to care staff what a child is *really* like and how he might react to his stay and to being separated from his family. They generally concentrate too much on defining disability and not enough on the child as a child. Some parents are embarrassed and distressed at having to fill in forms about their children. One mother described it as 'like the inquisition'. Another said that she was not convinced that just filling in a form meant that her child's needs would be met and that her wishes about his care would be faithfully carried out. She felt that using short-term care for her son was 'somehow sneaky', and answering written questions about his handicaps and incontinence was letting him down. The form she had to fill in concentrated so much on his poor abilities and his particular syndrome and negative aspects of his behaviour that she felt his identity as a child was completely obliterated.

All too often parents fill in forms which are just filed away and never seen by the care staff. In one hostel a child's form contained very important information about his bedtime routines at home, but the care staff were not told about this. They had not seen the form because it was put into the child's case notes and marked 'confidential'.

The reasons for form-filling need to be clarified. Is the information going to be used to help the children, and if not, then why is it being asked for? The information that parents give on forms, their wishes and suggestions, their tips about their children's care, should always be responded to with respect and be *seen* to be made use of. This means keeping children to their home routines as much as possible, letting them wear their own clothes, consulting with parents about programmes, keeping in touch with other professionals involved with the child. In this way the child's identity is seen to be preserved and his parents are not made to feel that they have betrayed him.

Children using Field Lodge mental handicap hospital were likely to lose identity because of the way their care was organised. They were put into hospital clothing immediately they arrived. For instance:

> 'Mrs O'Hara, a fifty year old widow, is very worried because her twenty year old son, Joseph, who has Down's syndrome, is always put into hospital clothing. She talked about this when I went to see her. I was in the ward when she arrived with him today and she tried

> to tell the charge nurse that she would like him to be kept in his own clothes. After she went the charge nurse referred disparagingly to her request. "Hospital clothes are better than the ones she puts him in anyway" he said.' (Extract from study observations 1979)

The charge nurse's remarks showed no sensitivity to the fact that taking Joseph out of his own clothes was against his mother's wishes, nor that keeping children in their own familiar clothing is important regardless of what the staff think about the quality of the clothes.

Field Lodge hospital was not the only place where children had their own clothes taken away. It was happening in a number of short-term care facilities. In one hospital each short-term care child had been assigned a set of hospital clothes marked with their own name, and they were put into these as soon as they arrived. Opening a cupboard and displaying piles of clothing the ward sister said, 'We have a progressive system of personalised clothing. All the short-term care children have got a bundle of hospital clothes kept ready for every time they come in'. The term 'personalised clothing' is used in long-stay hospitals to describe a system considered progressive because it means that the hospital issues clothing marked with a person's name instead of the residents sharing clothes from a general pool as so often happens in mental handicap hospitals. However, no matter how the system is described and disguised, taking away a child's own clothes is a very undesirable practice in child care because it is a throwback to the old institutional system of mass care.

Parents are reassured about a facility if they see evidence that it does not merely offer a bed but that the staff care about and like their child as an individual.

> 'The staff treat her like we do at home.' (Parents of a 13 year old girl using Rivermead local authority hostel.)

> 'We like Rivermead staff because they *know* our child and all her little ways.' (Parents of a six year old girl.)

Too much emphasis on the child being a burden to the family and society is not the best way to foster trust between parents and staff. Mr and Mrs Baker, whose five year old daughter, Jenny, was difficult to manage because she was so over-active (see also pages 67 and 130–131) were upset because they felt unable to convince the staff of their child's value as a person:

> 'We tell the staff about the little things she likes', said Mrs Baker. 'And her habits and the games we play at home. But they don't seem interested in anything *nice* about her, only in her bad behaviour. Once we said she liked vinegar crisps and we put ten packets in her case for her to have in the ten days she was there, but they took no notice, the packets were still in her case untouched when we picked her up again.'

The handling of the children's cases and belongings is very important to parents. During interviews and discussions they frequently mentioned how toys or special treasures had not been taken out of the cases:

> 'I sent in a little bag of toys with him. He went in on the school bus. And when I went to fetch him the bag was just hanging on a hook in his bedroom, it had never been opened for him and the toys got out.' (Mrs O'Hara, using a mental handicap hospital.)

Sometimes the treasures from home get lost or broken and this, to the parents, seems further evidence that the staff do not really care about their child as an individual:

> 'I used to pack his teddy, it would have been a bit of home for him. It had his name on it. But it got lost. Then I tried putting photographs in his case for him, to be pinned over his bed, but he kept being moved from cubicle to cubicle, even if he was in for only three or four nights, so in the end I had to stop that. The personal touch is always missing.' (Mrs O'Hara)

Relationships between parents and staff might be improved if staff were more aware of the pitfalls of stereotyping families instead of seeing them as individuals. Children are given labels, such as 'over-active and destructive' or 'a doubly incontinent helpless spastic' or 'an obese mongol'. And parents are labelled 'over-anxious', 'exhausted', 'unable to manage their child', 'full of guilt', 'rejecting', 'over-protective' and 'spoiling'. Such labels may be attached to parents bringing up ordinary children, but they acquire a particular prejudicial significance when applied to parents of handicapped children.

The following, from a written report by a social worker, illustrates how professionals make assumptions about parents:

> 'She finds the strain great at times, particularly during holiday

periods, but because of the *strength of her guilt* has not been able to let her child be cared for through short-term stress relief.'

The mother in question was doubtful about using short-term care because she was uncertain about the quality of care being offered in the facility and the effect that the separation might have on her five year old son. But this very normal parental worry about letting a small child stay away from home was never recognised; her reluctance to use the facility was seen only in terms of some sort of inborn 'guilt' about having a handicapped child. It is debatable whether parents of handicapped children do actually feel the instinctive guilt that many professionals so readily attribute to them. If they do have any guilt feelings these may well be caused by having to use poor services which they know are inappropriate, or even harmful, for their children.

The labelling of children and their parents often results in case notes and records being written in a strange mixture of social work jargon, medical facts and nursing notes, and the majority of them omit essential child-oriented information such as his nickname, the names and ages of siblings, his favourite food, whether grandparents are in close contact, whether there are married siblings and any nieces or nephews, whether the child has a garden, what are the names of any pets, what colour is the family car. Sadly, even when this sort of information is in the child's records there is no guarantee that it will be read by the care staff and made us of. (As referred to earlier on pages 4, 56 and 140, the forms filled in by parents about their children are often insufficient and/or are not made use of by the care staff.)

In none of the facilities visited during the research was there any one person who had been made accountable for interpreting the notes written by teachers, psychologists and doctors or by social workers and community nurses doing home visits, into terms which would help to improve the children's daily care or the contact between staff and parents. All too often the child in short-term care takes on a satellite existence, seeming to have no other life but his anonymous and temporary one in the short-term care facility. New staff going through a child's 'case notes' may obtain little more than a vague and negative picture of a helpless child belonging to over-protective, guilt-ridden parents, or a destructive child belonging to guilty parents who spoil him. And the daily notes kept on children during their stay often record little except changes in medication, bowel movements and sleep patterns. Their behaviour as children who laugh, play, cry, form relationships and get homesick are sparse or non-existent.

Ideally, if all records and daily notes were made deliberately *child-oriented* and contained comprehensive information about the family, they would help the staff to make relationships with the child and his parents. For example, if the names of the siblings and pets are known, these can be referred to when the child is being put to bed, so that he has a reminder of his family life and can feel there is a link between his home and the staff who are caring for him. Daily notes should also record the child's reactions to his stay and this information should be available to the parents.

Parents' groups attached to a facility may be a means of promoting shared management but sometimes these groups do not develop beyond a few coffee mornings, fund raising and open days (see also page 117). The groups may start off enthusiastically but gradually peter out leaving a nucleus of only four or five parents who support every meeting and grow bitter at the apparent lack of interest shown by most other parents. What do parents want from parent associations? Does attendance always fall off because of disappointed expectations, and is it inevitable for groups to fall back on innocuous fund-raising activities rather than looking closely at matters such as unit management and standards of child care?

Sometimes new staff make attempts to revitalise a flagging parent/staff association—'We are planning a series of coffee mornings to get more contact with the mothers', said a new sister of a short-term care ward. Fathers are often left out of plans.

In one health authority facility, some parents suggested that meetings might be held in turn at their houses, but this idea was opposed by senior staff who said that nurses could not leave the hospital during duty hours and should not be expected to attend meetings when off duty. It was also thought that staff would be at a disadvantage if they went to parents' homes for meetings as they might be 'manipulated by demanding parents with chips on their shoulders'. Senior staff often saw parent contact as a threat rather than a means of developing a trusting relationship between families and the direct care staff.

In another health authority facility the staff saw no need for a parents' group to be formed because, they said:

> 'Parents do not want staff in their homes or to meet them in the hospitals, mothers hold their meetings between themselves in the High Street and that is where they compare notes about services.' (Nursing Officer)

Unfortunately, parent/staff associations which are formed by staff may do little more than seal the long-standing authoritarian attitudes of professionals, discourage parents from passing any opinions and merely channel their energies into the activities of fund-raising and open days. It may be that professionals who have worked for a long time in institutions providing traditional long-term care find genuine difficulty in communicating with parents, for until the late 1970s it was common for children to be 'put away' into long-term care and uncommon for parents and staff to seriously consider the possibility of working together in sharing the care of the children. The following report of a meeting called during the first year of a short-term care ward being opened in a mental handicap hospital, illustrates the difficulties that some professionals find in relinquishing total responsibility and in knowing how to encourage parents and care staff to talk together and thrash out how they might develop a mutually satisfying service.

> *Monday evening*: A meeting took place tonight to form a 'Friends of Lindens' group (Lindens is the name of the ward). There was a mixture of parents, volunteers and nurses and doctors. Dr Emmerson (consultant psychiatrist) took the Chair. As she opened the meeting she said that everybody should feel free to bring up anything they wanted to say because it was an 'open meeting'.
>
> Mrs Pringle sat in the front. When I saw her at home last week she told me that she intended to come to the meeting and bring up the subject of how unfriendly the ward staff were whenever she brought her little boy in. She looked shy and nervous and it seemed to require a lot of effort for her to speak. Mrs Pringle said that she would like to ask why the staff were so unfriendly and about the children's clothes being lost, and why she could not come and take more part in her little boy's care, as she lived round the corner and would like to sometimes come and put him to bed herself.
>
> Immediately Mrs Pringle had said these things the atmosphere seemed to change. What she had said did not seem to be at all welcome, but Dr Emmerson made light of it, so did the sister of Lindens. She said, 'If mums want to come and help they would be welcome. We need extra pairs of hands any time'. As the sister was speaking, Dr Emmerson nodded and smiled around the room and after the sister stopped speaking the doctor put out her arms and regarded the parents for a moment in silence and then said, 'You must all look on me as your grandmother'.
>
> Then the other parents spoke up heatedly in defence of Lindens Ward and the sister and her staff, saying that they found it 'most friendly'. They glared at Mrs Pringle and she shrank back into her chair and looked upset. Then I said that Mrs Pringle's concern was not confined to this particular hospital but was a national problem and I had found parents in other areas also concerned about contact with staff at short-term care facilities they were using. I said that

short-term care was a new sort of service and the problems seemed to need some discussion. There was then a long silence, after which Doctor Emmerson said, 'What about sorting out what we need to raise funds for?'.

A father sitting at the back said, 'How about handing around the hat?'. There was some relieved sort of laughter. The father cleared the biscuit plate of biscuits and said, 'I'll start off by putting in this £10 note'. The plate was handed round the room, and people made contributions. Then a group secretary was elected and the meeting settled down to happily deciding on an object to raise funds for.

Mrs Pringle must have been left feeling she had been ungenerous to the nurses who were taking her child off her hands. The general feeling of the meeting was that parents were grateful and would not dream of criticising the hard-working staff. People were somehow made to feel sorry for the sister and cross with Mrs Pringle for having said that the staff were unfriendly and that she wanted to be more involved in her child's care and come and put him to bed.

It seems as if senior professionals want the parents to express meek grateful satisfaction with the rather poor service they are getting in Lindens Ward. And what is so depressing is that the poor service is wrapped up in the idea of the hospital being 'a centre of excellence' offering 'advice from a group of experts' and 'a collection on one site of tremendous expertise' (these were expressions used by Doctor Emmerson when she was opening the meeting). In reality the ward is not staffed by 'experts' but mostly by unqualified staff who are assisted in the evenings and weekends by young volunteers.

Tuesday evening: When I went to Lindens Ward this evening I saw volunteers (some as young as 13 or 14 years) pushing pap food into the mouths of cerebral palsied children. I could not help wondering why the professionals persisted in maintaining that the hospital was 'staffed by experts' when it was obvious that because of the shortages of staff the ward sisters were relying too much on the help of young volunteers to look after the children.

Wednesday afternoon: The sister of Lindens said that Mrs Pringle came to the ward this morning and 'apologised for the things she had said at the meeting on Monday but said some equally horrid things again about the children's clothes'. But she had 'agreed to help the nurses by coming to the ward and sewing buttons on clothes'.

Mrs Pringle's attempts to be involved in the ward and her own child's care and have some say in the quality of care offered had been

> misinterpreted, regarded as destructive, and she had been relegated to the role of a volunteer—helping the nurses by sewing on buttons. (Extract from study observations)

The lack of constructive communication between parents and staff at the meeting was probably caused because in that hospital, as in so many other short-term care facilities, the patterns of care were based on the old philosophy of taking over the children and excluding the parents, as had happened for so many decades in long-stay hospitals. Perhaps the lack of contact between parents and staff arises because short-term care services are still very much in their infancy and because many of the people providing the service are steeped in long-stay hospital traditions. The retreat from constructive critical discussion into fund-raising activities seemed to signify the wish of professionals and parents to escape from facing the problems of how to work together in this very new type of service. Fund-raising activities are safe, pose no threat to professionals, do not require parents to be critical, provide an instant opportunity for innocent activities and do not cause embarrassment. Mrs Pringle's criticisms embarrassed, she seemed to be rude to staff, and the parents felt uncomfortable at what she said, so they consequently sided with the staff against her and she was left feeling guilty at having upset the staff, and the staff felt indignant at her criticisms.

The reactions of the staff and the other parents to Mrs Pringle's criticisms were rooted in what I here describe as *the gratitude factor*. Professionals and parents fall too eagerly into the roles of *the givers* and *the grateful*, and thereafter behave towards each other in the manner each expects, and this prevents any radical, or even mild, criticism of services. The roles are based on certain assumptions: that the children are very difficult, that the parents are exhausted and incapable, that the staff have expertise and can take over the children's care. These assumptions are also linked to the labelling of the parents and the children (see also pages 142–143). Thus, the staff fall into the role of being 'the experts' (no matter how inexperienced and poorly qualified they might be), and the majority of parents fall into the role of being grateful and will meekly accept poor care and even make excuses for the staff if things go wrong, and they will oppose any parents who criticise the services. But gratitude, meekness and blind acceptance are not the ingredients to encourage parent management and mutual trust.

The findings of this report suggest that short-term care is, in fact, a very insidious service, for it can encourage professionals' authoritarian attitudes and can errode parents' responsibilities. If staff and parents do not make mutual efforts to discuss the quality of short-term care, and if they do not keep themselves aware of the pitfalls of assuming the out-dated roles of the givers and the grateful, the service will never develop beyond what I call *a separation service.* And a service which aims to merely separate, and lacks a firm philosophy of mutual sharing and trust, and discourages critical appraisal, will ultimately harm the children. In Chapter 6 the care of the children is examined and in some instances shown to be very poor. Poor care might have been prevented if there had been better contact between parents and staff.

The care of the children would doubtless be improved if care staff could find more time to listen to parents and develop sensitivity to their very normal worries about being separated from their children. The following letter was written by a mother to the sister of a small locally based health authority unit when her six year old daughter was going in for short-term care.

> 'Dear Sister,
>
> Just a few things that you may find useful with regard to Carol.
>
> She usually goes to the toilet as soon as she gets in from school. She will make 'uncomfortable' noises, not crying—more of a grunting sound, and when asked if she needs the toilet will nod yes or no.
>
> At bedtime, approx. 8.15–8.30 pm, she is happy with three rusks and half a cup of warm milk. She has her cup with her in her case.
>
> She sleeps on her side, knees bent and with Paddington tucked under her chin, and the bedclothes pulled up round her ears. She usually needs to be turned over at least once and usually goes to the toilet between 5 am and 7 am.
>
> She eats two rusks at breakfast and has a cup of tea. She goes to the toilet again about 8.45 am before school. She also likes to take her boots off at teatime and put on slippers. Carol is not afraid of the dark.
>
> I hope this may be of help to you. I will telephone to see how things have been.
>
> Yours sincerely,'

The mother's description of Carol and the gentle but decisive tone of the letter showed a quiet confidence that the staff were interested in her little girl's ways and would follow the advice. The letter exemplifies the trusting relationship that can be developed between parents and care staff. This particular unit was well known for providing a comprehensive support service for local parents of handicapped children. They were always welcome in the unit, and one room had been set aside for them to use for meetings or any other purpose. The care staff visited families at home and the professional staff of all disciplines were readily available to help parents as necessary.

Summary and conclusions

Parents are not sufficiently involved with the short-term care units they are using; they do not have a voice in setting standards or defining practices.

A surprising number of parents do not know the names of the staff who are regularly caring for their children. Locally based units are more conducive to parent/staff contact; the larger the organisation the less were staff known to the parents.

The undesirable practice of sending children to and from units on school buses, via school, may mean that the parents never visit the units themselves and never get to know the staff.

The gap between parents and staff can be caused by staff movement and hierarchy, the organisation of staff time, and attitudes of staff towards parents.

The handling of the parents' initial introductions to units is crucial to building up good relationships. Staff need to be aware of the importance of always introducing themselves to parents and always being friendly. Some parents describe staff as being short-tempered, not having time to talk to them and making them feel a nuisance when they are worried about their children being away from home.

The majority of parents want to be much more involved in their children's care and want to be told the truth about their stay. But communication between parents and staff is sometimes so bad that decisions are made about the children without the parents being consulted, such as giving children hair-cuts or medicine.

Parents sometimes lack information about the units they are going to use for their children, and they do not know if the staff are qualified and experienced, or if their children can wear their own clothes, or the arrangements about outings or sharing rooms. A leaflet describing the facility can be very helpful, but some leaflets are very poorly written.

The forms that parents have to fill in sometimes concentrate too much on the children's disabilities instead of on their strengths. Too much emphasis on the children being a burden and a bother can influence staff attitudes. There is a tendency to stereotype the parents and their children. This is reflected not only in the forms that the parents have to fill in about their children but also in the writing of case records, in which derogatory remarks are sometimes made about children and their families.

Staff/parent associations can be helpful, but they need to define their aims very clearly and offer parents opportunities for critical discussion if this is what they want. Some associations fail because neither the parents nor the staff have the confidence to throw off the old roles of the givers and the grateful.

Short-term care is a professional service which is still very much in its infancy. Staff and parents must be prepared to work together at defining the aims and objectives of the service. Close contact between parents and staff is absolutely vital. The dividends of a trusting relationship are mutually rewarding.

References

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6 Children receiving short-term residential care

> 'Let's face it—the care is to benefit the family and not to benefit the child. In fact it probably has adverse effects on him—and us knowing it does him no good are not helped to relax properly when he's there, are we?' (Parents using a mental handicap hospital ward for their nine year old son with Down's syndrome.)

> 'Leaving their family is not so much a problem for mentally handicapped children as for normal children. These sort of children live in the moment and do not suffer the same upset as normal children. They do not think about what is happening so do not worry about it.' (Officer-in-charge of a local authority short-term care hostel.)

> 'The staff don't get *inside* the children.'
> (Mother of an eight year old girl, handicapped by Rubella.)

What do the children think about having short-term care? How is it explained to them? How much do they understand that the reason for their going away is to give their families a rest? Do they feel a sense of rejection? The sensitive handling of children's separation experiences is a basic principle in child care, but the feelings of mentally handicapped children who are being put into short-term care are often overlooked. Indeed, it seems as if they are not expected to have the same emotions as ordinary children. From observations made during this study there is reason to believe that short-term care can cause stress for the children—stress which is being denied by parents and professionals and having adverse effects that are insufficiently recognised. The children may suffer from feelings of insecurity and rejection, and become very confused by the experience, especially if, as so often happens, their admissions are organised in a furtive way to avoid upsetting them.

Parents were asked how they told their children that they were going away for short-term care. Some explained it as 'a holiday' or 'visiting friends' or 'going to see your aunties'. Some used the name of the place or just said 'the hospital'. Some did not attempt to explain it to their children, either because they did not believe that they would understand or they thought that an explanation would upset them.

It was obvious that the children who had some understanding of language, time and place, were not receiving adequate and honest verbal explanations about why they were going away from home and for how long. And the more profoundly handicapped children, whose understanding of time and place was limited because of their very severe mental handicaps (some being blind, immobile, deaf and speechless) were not being given the special considerations which might have made the experience of leaving home a less frightening one (see also page 177). Children who were blind and deaf and spastic, who depend so much on the feel and smell and sounds of familiar surroundings, were not only being admitted to wards which must have felt, smelt and sounded very alien, but they were sometimes not even permitted to wear their own clothes. The retention of familiar belongings and routines should be accepted as an essential practice in caring for profoundly handicapped children away from home.

Not *all* children are thoughtlessly treated when in short-term care; some of the observations made during this study showed children having a relaxed and happy time with staff who were aware of their needs, and their parents were justifiably satisfied with the services they were receiving. However, the study observations also revealed many examples of child stress being neglected and some very poor standards of child care. This chapter does not describe good practices, but concentrates on evidence, or suspicion, that there is much unhappiness amongst children who are receiving short-term care.

There is a need to draw attention to the negative aspects of short-term care because the service is expanding rapidly and parents and staff should be alert to the dangers of the bad practices which bedevil it. One of these bad practices is that very young children are receiving regular admissions into mental handicap hospital wards or hostels where they are stripped of their familiar routines and clothes and have minimal mothering attention. Abdul, a severely cerebral palsied child, received 12 such admissions to a crowded mental handicap hospital ward from the age of 18 months to three and a half years old, each admission being for a period of between one and eight weeks. If normal young children were given repeated hospital admissions they would be expected to show some adverse reactions, but it was assumed that Abdul would not be affected because he was so mentally handicapped. For many children the experience of short-term care must be like a recurrent bereavement, a bereavement made worse because their signs of grief are unrecognised.

The stories in this chapter have been drawn together from observations made in the units which were visited and from the discussions with parents and staff. They illustrate what short-term care may be like for the children and how it may be affecting them.

When Olive came in with mum and dad she seemed a bit clinging. On the following day I noticed her playing, but always on her own, with dolls and a carry-cot. At about 3 pm she sat on a chair in the corner, turned her face to the back of the chair and cried a great deal, saying over and over again to herself: 'I want my mum. I want to go home. I want my mum. Go home'. (Observation made during study: 14 year old girl with Down's syndrome.)

Emma's behaviour changed over the day, from weeping and clinging and asking questions of anybody who had time to listen, to slightly more aggressive behaviour, bossiness, answering back, masturbating in the middle of the room, insisting on brushing adults' hair, although requested not to. Always, during the gentle weeping periods and the more aggressive behaviour, she kept asking about home and mummy. (Observation made during study: ten year old girl with Down's syndrome.)

Tess had a repertoire of little sayings which she played with her parents. They would say 'Fish and . . .' and she would say 'chips'. Or 'Round and round the garden like a teddy . . .' and she would say 'bear'. These small sayings were her only ability; she was totally immobilised. Her parents had told the staff about this and they thought that during her weekend in short-term care the staff would play with her in the same way they did. But she was not spoken to in this familiar way during her weekend stay; in fact she was not given any attention except when she needed to be changed or fed or washed. (Observation made during study: 14 year old, totally disabled girl.)

During three hours on Saturday, Cath was not given any attention. She sat with Jack at the other end of the room, by the record player which was turned up at deafening volume all the time. On Sunday she sat alone on a swing outside the ward for most of the day—nobody went to her except to feed her or to bring her in to be changed. She looked very white-faced and strained; her eyes were full of yellow dried discharge and she appeared to be very uncared for. (Observation made during study: 16 year old, severely handicapped girl.)

Ivan lay on a sag bag for three hours in the same position. Sometimes he opened his mouth and half laughed and half cried in the manner that cerebral palsied children sometimes do. Occasionally when he did this one of the staff would say, 'We don't want to see your breakfast Ivan' and this made him do it again. But nobody went to

> him or touched him or moved him. This joke about his breakfast was the only social contact anybody made with him. At meal times he seemed to pose special problems. During breakfast time one day the sister grumbled loudly about how difficult he was: 'I would not give him to my worst enemy to feed' she announced loudly to everyone in the room as she stood feeding him. I asked if his mother had been invited to the ward to show the staff how she gave him his meals, but was told 'No, she's supposed to be having a break from him'. There was repeated arguments about how to manage him. Some of the staff said 'Just lay him down flat on his back and tip his head back', whilst others said 'No, the physio doesn't like us to do that'. His mother had told me that she always sent in a packet of biscuits with him as he liked one after every meal. There was no sign of the biscuits and his routine of having one after meals as he did at home. It was enough that the staff could do to get a few slops poured down his throat. (Observation made during study: 15 year old boy with multiple handicaps.)

The following observation of Nelson, a 13 year old, severely mentally handicapped boy receiving short-term care in a ward accommodating 20 long-stay multiply handicapped children, describes a few hours of his final day of a week's short-term care:

> At 9.45 am there were only two children in the dayroom, the others were either in the bathroom or bedroom, being tidied up after breakfast. Nelson was sitting in a plastic armchair with wooden arms. Ted, a cerebral palsied child who had been living in the ward for ten years, sat next to him. Nelson was holding an empty cereal packet on his lap. The nurses were either in the bathroom or bedroom. He stood up and took some tottering steps forward, squeezing his carton. He plonked himself down on a sag bag and started to stare at the carton very intently; now and again he nuzzled at it. Then he stood up on the sag bag, swaying unsteadily and stared hard at the television screen which was only a few inches away from his face. He stood in this position for five minutes. At ten o'clock he wandered into the bedroom and sat down on a bed beside one of the children who was being changed. A student nurse decided to change his trousers. At five past ten he wandered back into the dayroom, prodding his cereal carton and once again he stood on the sag bag. He stood there for twenty minutes. At 10.25 am he was crawling about with his cereal carton, pushing it along on the floor before him. At 11 pm he went out into the courtyard and walked aimlessly around there for 50 minutes. He took no notice of the other children who had been taken out there to sit on mats earlier in the morning.

At 11.50 am a nurse brought Nelson in from the courtyard and sat him at a table to have his lunch.

At 2 pm he was sitting on the floor in front of two school-girl volunteers who were folding nappies and sorting socks from two clean laundry bags. Nelson sat patting the laundry bags as the two volunteers chatted to each other. At 3.05 pm he moved away from the schoolgirls and crawled towards the television set and sat beneath it; he was still holding onto his empty carton and he patted this continuously. At 3.45 pm he was still in this position. Then a nursing cadet went towards him to change him into his 'going-home trousers' (he was dressed in hospital clothing during the time on the ward, only wearing his own clothes when ready to go home). He was soon to be taken home by a volunteer driver. The nursing cadet stood him up and began to pull his trousers down. The deputy charge nurse saw this and called out 'Don't do that out there, take him into the bathroom and do it'. The cadet walked him slowly into the bathroom, his trousers over her arm. At 4.10 pm he was brought out of the bathroom dressed in his own clothes ready to go home and handed over to the voluntary driver.

Nelson had been having a very boring and lonely time. The only time he had been noticed was when he needed something to be done to him, such as having his lunch or being changed. He had stood or sat by the television set, he had sat patting his cereal carton or pushed it about the floor; he had sat patting a laundry bag, he had wandered into the courtyard. Nobody had taken any notice of him or made any effort to talk to him or play with him. The only advice concerning his care, given by a senior to a junior member of staff, had been about where his trousers should be changed, not about how to play with him or give him any mothering.

Nelson's loneliness highlights the inevitable problems which are caused by collecting a large group of handicapped children altogether on one site. Admitting short-stay children to long-stay wards and hostels which are already under-staffed and crowded with long-stay children is not a good practice. Long-stay children living in hospitals have usually been deprived of a normal life for many years and the addition of homesick short-stay children can do nothing but add to their problems, and to the problems of the staff who are trying to provide some semblance of a normal life-style under inappropriate and often quite bizarre conditions. Research has shown that children living in mental handicap hospitals receive an average of only five minutes 'mothering' attention every ten hours.[1] It would therefore seem very wrong to admit any handicapped child to a hospital for residential care, whether the care is to be permanent or temporary.

Some staff who are working in long-stay wards and hostels admit to having less sympathy and interest in the short-stay children because they seem to be demanding and 'spoilt' and just an additional burden on top of all the problems caused by the long-stay children. The following remarks illustrate these opinions:

> 'I give my priority to my long-stay children. If I am honest perhaps I would say that I even resent the short-stay ones because they interfere with the routines I have got going for the long-stay ones.' (Care assistant in a long-stay hostel accepting two or three short-stay children at a time all the year round.)
>
> 'We never take the short-stay children on outings because they can always go out when they are at home with the parents.' (Nurse in a long-stay mental handicap hospital ward accepting three short-stay children at a time all the year round.)
>
> 'Taking in short-stay children is OK. We like to help their parents. But I can't say they appeal to me much as individuals as they always seem so grizzly.' (Nurse in a long-stay hospital ward.)

The following observation of Penny, who was having short-term care in a mental handicap hospital, shows the stress and disruptions which children may have to suffer when they are given short-term care in a place which is not geared to their needs:

> Thirteen year old Penny is having a week's short-term care in the ward. The other twenty children are all long-stay. She is cerebral palsied and non-ambulant, but she is able to speak. Each day she goes to her school in the town. Today she came back to the ward at 4 pm. *From 4 pm until 5 pm* she sat in her wheelchair in the middle of the ward in the position she had been put in by the bus escort who brought her back from the school. At 5 pm all the children had their supper. Penny could feed herself.
>
> *Between 5.45 and 6 pm* she was in the bathroom, with 11 children who were being got ready for bed, having baths, and being put on pots and toilets. Penny was not got ready for bed because she was expecting to go to her club for disabled children which she belongs to in the town. She regularly attends this club one night a week when she is at home and it was hoped that she could continue to do so, from the hospital, during the week she was in for short-term care. *At 6 pm* she was back in the ward from the bathroom, dressed and ready to go to her club. Her wheelchair was placed near the ward door so that she would be ready for the volunteer who was supposed

to be picking her up to take her. She was told, 'Wait by the door here for your lady to come'.

All the long-stay children milled aimlessly about the ward, some dressed in night-clothes, some waiting to be taken to the bathroom and changed. The television was put on but only Penny watched it, from her spot by the ward door.

Between 6.30 and 7 pm Penny began to get visibly anxious because the transport and voluntary escort had not arrived to take her to the club.

At 7.10 she was spoken to by a male nurse as he passed her chair. He said 'Your lady is fetching you for your club isn't she?'. Penny nodded rather wanly. This was the first time anybody had spoken to her since she had been placed there to 'wait for the lady' at six o'clock.

At 7.20 Penny was still waiting to go to her club. She looked very near to tears. Her chair was still in the same place. She had been waiting patiently for an hour and 20 minutes and had had no explanations about why the woman with the transport had not turned up, and nobody had reassured her that they would telephone and see what had happened about the arrangement.

At 7.55 Penny was still waiting, trying to turn her head anxiously in the direction of the ward door to see if anybody was coming for her. Long-stay children were being put to bed by the nurses.

At 8.10 Penny was the only child still in her clothes. Five long-stay children sat in their night-clothes at the end of the ward by the television; the other 15 children had already been put to bed. Penny was still waiting in the same place by the door. She was now crying.

At 8.30 Penny, crying bitterly, was pushed more into the middle of the room. Nobody told her what was happening. She had not been spoken to for more than an hour, and for two and a half hours she had been waiting to be picked up and taken to her club.

At 8.40 a student nurse going off duty spoke to the night nurse just arriving for duty and told her that it was not likely that Penny would go to her club now and that she might just as well be put to bed.

Lionel, observed in another long-stay hospital, was also suffering stress:

Lionel aged four, is in the ward for a fortnight's short-term care. He does not get the attention he is craving for. The staff find him a burden and do not like his perpetual weeping. 'He gets too much attention at home, so when he is here he must learn to do without all that spoiling' they said today. From the age of one year to just four

> years old, Lionel had had thirteen 'social admissions' (as they call short-term care in this hospital). Each admission lasted from between two days and eight weeks. Considering the uncertainty and insecurity of his life-style in the last few years it is small wonder that he is tearful and unhappy, but the staff seem surprisingly unsympathetic to his plight. (Observation in a long-stay hospital ward.)

The observations of Penny and Lionel present a sorry picture of children away from home, showing them to be lonely and homesick.

More than half the 123 parents in the study said they thought their children were probably homesick when they were having short-term care, and that the experience seemed to have adverse effects on them. Some of the parents were upset when reference was made to the likelihood of homesickness and they hastened to change the subject.

None of the parents had had opportunities to discuss the possibility of their children being homesick or the normal effects of a separation experience on young children, such as the likelihood of it causing bed-wetting and disturbed sleep.

Not all the parents were able to give specific descriptions of how their children seemed affected by the short-term care, but many mentioned that they had noticed changes in them, such as 'much quieter', 'didn't sleep so well afterwards', 'tired', 'noisier', 'gone back, got babyish again'. Some were able to describe definite reactions:

> 'She was strange when she came back. She kept staring round the room and wouldn't let me leave her or go out of the room at all. She kept wanting to be picked up and she cried a lot.' (Mother of a two year old, cerebral palsied child.)

> 'Short-term care seems to make him bad-tempered and demanding. He cries a lot when he comes back and seems somehow depressed.' (Mother of a ten year old, cerebral palsied boy.)

> 'She didn't want to know me for a week when she came home again, but was alright with Dad.' (Mother of a three year old, multiply handicapped girl.)

> 'She started wetting in the bed and on the settee. And was staring round the house and very quiet for about a week.' (Parents of a 14 year old, severely mentally handicapped girl.)

> 'He went on the Friday. We were told not to visit him as we had to get a proper break. My neighbour visited him for me on the following Tuesday and Thursday. On the Tuesday he was excited

> and took her round the bedrooms and dayrooms and played with her. On the Thursday, however, she felt he was beginning to feel he'd been away from home a long time. He clung to her. He had never been away from home before. He was very subdued when he came back.' (Mother of a 13 year old boy with Down's syndrome.)

> 'He was laughing a lot when we fetched him home, kept on laughing and laughing when we got back. But it was a different sort of laugh to his usual one. He kept wetting too, wetting and laughing all at the same time.' (Parents of a four year old, mentally handicapped boy.)

> 'She can't really express it but I think she resents it. She asks every morning now "Have I got to go to the hospital? I'm not going" and she keeps smacking her brothers.' (Father of a ten year old, active mentally handicapped girl.)

> 'Very quiet. He sits on the stairs a lot when he comes home and seems to need several days to unwind.' (Mother of a 12 year old boy with Down's syndrome.)

Children with profound handicaps caused by severe cerebral palsy with its often accompanying immobility, blindness, deafness and lack of speech, were frequently described as being very withdrawn after periods of short-term care. No matter how old they were or what sort of facility they were using there was a *certain similarity about their reactions which seemed to suggest that severely multiply handicapped children experience a deep grief when they are away from their familiar surroundings and families.*

> 'She did not respond to us for two weeks when she came back. She was completely switched off.' (Parents of a four year old, blind, cerebral palsied child.)

> 'The longer he stays away the further away he seems to be from us when he comes back. He seems very *distant*. He has never been away longer than a week.' (Parents of a six year old, profoundly handicapped boy.)

> 'He can't say if he gets homesick, but he is passive and withdrawn for about two weeks afterwards.' (Mother of an 11 year old, blind and deaf boy.)

> 'When she comes back she seems different. She takes about three days to recover and sits in the chair looking very lethargic. She is like

> a snuffed out candle.' (Mother of a seven year old, profoundly handicapped girl with Down's syndrome and partial sight.)
>
> 'She cried non-stop for ten days when she came back from ten days short-term care in the hospital. She used to go every few months and there was always the same reaction. Our GP said he could find nothing wrong with her to cause that non-stop crying, and that it must be a reaction from homesickness.' (Parents of a seven year old, severely cerebral palsied girl.)
>
> 'He comes back all dead. No smile anymore. I can't get through to him for several days, there is just no response at all.' (Mother of a three year old boy, cerebral palsied and blind.)

Parents described how their children reacted when they saw them arriving at the units to fetch them home again:

> 'He bursts out crying when we fetch him, as soon as he hears Mum's voice.' (Father of a five year old, mentally handicapped boy.)
>
> 'When I arrive to fetch him he runs into a corner and hides from me, and seems as if he doesn't want to know me.' (Mother of a 12 year old boy with Down's syndrome.)
>
> 'She cannot move at all on her own, but when she sees us arrive to fetch her home there is a definite whole body movement towards us, as if she could fling herself on us if she could walk or run.' (Parents of a three year old, severely mentally handicapped child.)
>
> 'He cries and clings when we leave him but it is almost worse when we fetch him. Immediately we arrive he hurtles across the room, insists on being picked up and will not allow us to put him down again until we all go out to the car and he is absolutely sure that we are all going home together.' (Father of five year old boy with Down's syndrome.)

Some parents referred to their children going happily into short-term care the first time but showing signs of resistance and stress when they were taken in on the second, third and subsequent occasions:

> 'The second time we took him he fought, grabbed the car door and wouldn't get out.' (Father of a six year old deaf, mentally handicapped boy.)

> 'He was OK the first time we took him. He'd not been there before and I suppose he did not understand about his case being got ready and so on. But now whenever we get ready to take him he grabs his case and keeps trying to unpack it.' (Mother of a six year old, mentally handicapped boy.)

> 'When we arrive there now she pulls back and tries to get back into the car and then sits down and won't walk at all.' (Parents of an eight year old girl with Down's syndrome.)

Sometimes a child is taken to the short-term care unit by only one parent because the other finds the parting too painful.

> 'Dad was so upset the first time he said he could not face it again, so I always take her on my own. She hates being left and she struggles and won't get out of the car. One of the staff helps me with her.' (Mother of a 13 year old, cerebral palsied girl.)

> 'When she feels the car go over the no-speed bumps in the hospital drive she tenses up and struggles. She won't be lifted out of the car and goes all stiff. The car *rocks* with all the struggles. All this started after she'd had three turns of short-term care. Mum won't go there now as she finds all the fuss too upsetting.' (Father of a 14 year old, profoundly handicapped girl.)

Painful upsets when being left or fetched home again are often the reason why the parents decide to use school transport to get their children to and from the units. In this way they can avoid witnessing their child's stress.

> 'Whenever I fetched him he used to run up and sob as if he had been beaten for 24 hours. I always used to take him and fetch him myself, but in the end I got so upset by his tears that I decided to let him go in and out on the school bus.' (The widowed mother of a ten year old boy with Down's syndrome.)

> 'She started screaming when she saw the gates of the place, hanging back and sitting on the ground. We got like limp rags, so she always goes on the school bus now.' (Parents of a seven year old girl with Down's syndrome.)

The decision to use school transport to get children in and out of short-term care is generally thought to be an excellent arrangement, and will be agreed between any number of the adults involved with the children—parents, social workers, community nurses, care staff, teachers—but the likelihood of the arrangement upsetting the children seems to be completely ignored. During the study I travelled on school buses and noticed the children's apprehension when the drivers did not take them home as usual, but drove off in another direction to take them to a hostel. In one instance a six year old child became extremely upset when she found the bus going past the end of her road instead of turning down it and taking her home. She tried to attract the attention of the driver and escort, saying 'Home, home down there. Go home', but her cries were ignored and she was taken on to the short-term care hostel where she arrived in a state of tears and distress. It must be very difficult for small children who are mentally handicapped and inarticulate to understand why the school bus, which usually takes them home, suddenly goes in another direction and delivers them to an unfamiliar place where they cannot find their families. (The use of school transport to get children in and out of short-term care has already been referred to as an undesirable arrangement because it reduces parent contact with staff, see pages 120, 124–125, and the effects on the children is again referred to on pages 164–166.)

Some parents described how their children seemed to lose confidence after experiencing short-term care, becoming *generally apprehensive* and seeming to *anticipate further separation* in activities which they had previously enjoyed:

> 'After having three goes at short-term care she began to get very apprehensive about *everything*. Making a fuss about being lifted out of the car, even though we were only visiting friends. She never did that before.' (Parents of a 14 year old, profoundly handicapped girl.)

> 'When he came back after being there for the first time (he was there for two weeks), he started to say 'Mummy gone?' to me at home. He would follow me around saying it. He'd never said it before. He seemed anxious all the time. He always cries when we leave him there.' (Mother of a four year old, active mentally handicapped boy.)

> 'She was very clinging for about a week and was not happy about going up there for day care which, until then, she had always enjoyed. She had been having day care there a couple of times a week for about 18months before she slept there, but immediately she slept there she seemed to go off the place altogether as if something had frightened her.' (Parents of a four year old girl with Down's syndrome.)

> 'He cries now when I take him to places he used to like, such as down the supermarket. He thinks I might leave him I suppose. He whimpers in the doctor's surgery too. He never did that before he started to have short-term care.' (Mother of a ten year old, mentally handicapped boy.)

> 'He seems more tearful nowadays, always watching to see what's going to happen. On Monday mornings he keeps looking round and staring to see if his wheelchair is being put into the school taxi.' (Mother of a 16 year old, profoundly handicapped boy.)

> 'He does not trust people as much as he used to. He makes scenes in school now and won't always get into the bus, even though it is not always taking him to short-term care.' (Mother of a 12 year old boy with Down's syndrome; she was worried by his withdrawn behaviour at home and by complaints from his teachers that he was difficult about getting into the bus after school.)

> 'He keeps following me around the house everywhere when he comes back, and will not let me out of his sight even to go to the loo. And he's reluctant to get on any buses now, since we started letting him have short-term care straight from school. (Mother of a seven year old, mentally handicapped boy.)

> 'She seems very worried generally. She cries a lot and keeps asking, 'No more, no going again, no more?'. (Mother of a 14 year old, mentally handicapped girl.)

The children's newly developed apprehension was often expressed when on journeys which took them near the short-term care units:

> 'When we go out shopping on Saturday mornings she bursts out crying when we reach the roundabout at the end of the road leading off to the hostel, although we tell her that we are not taking her there.' (Parents of an eight year old, mentally handicapped girl.)

> 'Every time we go for drives now he gets very anxious, and he screams and yells when the car passes the end of the road leading to the hospital, even when we are not going there. This happened recently and I held him and found that his heart was pounding. Whenever he sees the traffic lights at the right turn for the unit he screams.' (Mother of a ten year old boy with Down's syndrome.)

The mother of one child became so worried about him being upset when driving near the short-term care unit that she went to the staff to seek an explanation for his behaviour. She thought that he must have been frightened, hurt or grumbled at during one of his stays there. The staff were very upset, thinking that the mother was accusing them of neglecting him and they set about disproving any idea of poor care. Bad feelings then developed between the staff and the family. Neither the staff nor the parents seemed to recognise the fact that the child's apprehensive behaviour was a very normal reaction to separation in early childhood.

If the staff and parents had been helped from the beginning to *recognise that homesickness reactions are normal and to be expected*, perhaps some of their suspicious and defensive feelings might have been avoided, and they could have worked together to ease the child's stress about his separation. However, a mentally handicapped child's normal feelings of homesickness are frequently denied, and if there is any disturbed behaviour after he returns home the staff tend to blame his mental handicap or say that his parents mishandle him, whilst the parents blame his mental handicap or say that the staff have mishandled him. Neither groups pay sufficient attention to the *normality of disturbed behaviour* after a child has experienced a separation.

The pain of acknowledging the evidence that their children are upset by short-term care is very upsetting for parents. Some said that they had always thought their children liked the hostel or hospital they were using and they were astonished when they began to suspect that they might be homesick. The parents of a nine year old boy said:

> 'We were going for a drive to the park one Sunday afternoon and when we got to the roundabout turn off for the hospital he got dreadfully upset and obviously thought he was going there. We felt awful about it because we'd always thought he enjoyed it. He'd been going in on the school bus each time and we never worried, but then we began really wondering and worrying about him and whether he was crying all the time he was there.'

The realisation that short-term care causes stress for their children is not easy for parents to accept. They fear that there will never be any other form of help available if this support service fails and their children do not like it. This fear, coupled with the realisation that they are using a service which actually upsets their children, may well trap the parents into denying the homesickness.

The parents of five year old Gwen Davies said: 'She has no reaction at all to being in short-term care. She loves it'. Yet observations of her behaviour in the hostel showed her to be anxious and weeping and constantly running up to the windows and doors asking 'Car coming, Mummy here?'. And she wept bitterly in the school bus as it took her past the end of the road where she lived and on down the road to the hostel. Gwen's teachers reported her as being 'very disturbed' since she had started having short-term care. She was described as more tearful in her class, wanting cuddles and attention from the teachers. She was also reluctant to get onto the school bus, and had to be carried on, clinging to the teacher, and saying, 'No hostel, no hostel, go home to mummy'. The teachers decided, after a while, to hide her case in the schoolroom cupboard on the days she was going into short-term care because if she saw it she would cry all day and ask to go home.

The teachers had been to the hostel and spoken to the care staff about Gwen being unhappy about going away from home. The care staff agreed that she probably got homesick, but said the parents needed a break from her. The teachers had also spoken to Gwen's parents about her homesickness, but they had denied any likelihood of it. The teachers eventually felt that there was nothing more they could do, as the parents and the care staff did not seem to be worried about the little girl's unhappiness.

Gwen's very normal unhappiness at being separated from her family was probably made even worse by:

a The inability of everyone (teachers, care staff, parents, social workers, bus escort) to share information about her reactions, recognise her stress and come to some agreement about how to ease it; and

b the insensitive arrangement of making her go to the hostel on the school bus which actually drove past the end of her road. This must have been a frightening experience for her.

Gwen's story is a sad example of many adults being involved in one child's life but none of them really sharing information about her feelings. Only the child herself knew the full story. The adults saw only a fragment of the whole picture. When all the fragments were fitted together, through the interviews with the parents, visits to the schools, discussions with care staff and teachers and the observations in the hostel and the school bus, the picture that emerged was of a very homesick and distressed little girl. In fact, the short-term care that everyone had assumed was such a good idea was the cause of considerable stress to Gwen.

In order to prevent this sort of situation, all the involved adults should communicate with each other regarding the children's reactings to short-term care, and they should regularly reconsider the arrangements made for their admissions. And in the case of younger children, it is most unwise to put them to the strain of going to and from short-term care on school buses that take them past their own roads. It is also unwise to start them on short-term care *during their first year in school*; starting school is an experience that requires a great deal of social and emotional adjustment from any child, and it is very hard on children who are mentally handicapped to expect them to endure the additional strain of adjusting to a residential care experience during their first year in school—such a dual adjustment is not demanded of young children who are *not* handicapped.

The staff of the children's schools often have relevant information about the children's reactions to short-term care, but they are not always asked for their opinions. Teachers in the 15 special schools visited during the study said they thought the experience of short-term care could be very upsetting for some children. They reported disturbances in behaviour ranging from unusual quietness, weeping and anxiety, to outbursts of quite violent behaviour. One teacher said that a 14 year old active boy became very disturbed on the Friday afternoons when he knew he was going to the mental handicap hospital for short-term care straight from school; sometimes he would become almost unmanageable and the rest of the children in his class would have to be taken over by another teacher so that he could have one-to-one attention from his own teacher. Throughout the afternoon he would cry and shout and throw over chairs and then refuse to get into the taxi when it came.

During the visits to families and facilities, the children were sometimes asked about the hostel or hospital but they were not formally questioned about their feelings regarding short-term care because so many of them were either very young and/or very mentally handicapped and speechless. Those who could speak were occasionally asked a question such as: 'Did you like it at Collingwood?' or 'Did you have a nice time in Magpie Ward?'. Sometimes they smiled and repeated the name of the facility or gave answers which were prompted by their parents, as the following little girl did:

> *My question:* 'Did you like it at Collingwood?'
>
> *Mother* (sitting with Margaret, aged six, on her lap): 'Collingwood, you like going there don't you?' (Then, holding up one finger) 'Stay one night.'
>
> *Margaret* (holding up one finger) 'Collingwood, yes, stay one night.'
>
> *Father* (putting his head sideways onto his folded hands) 'Collingwood, have one sleep there.'
>
> *Margaret* (putting her head sideways down onto folded hands) 'Yes, one sleep.'

Thus, with signs and smiles, do some parents talk about short-term care to their children, reassuring them about their stay but not necessarily being able to find out what they think about going away.

Seven year old Sally became very excited when she got out of bed late one evening and found me talking to her parents. She recognised me from being in the hostel the week before, when she had stayed there for three nights and enjoyed playing with water. Her parents said, 'This lady is from Rivermead' and Sally said, 'Water, make bubbles', obviously remembering her enjoyment with the water. But when 12 year old Nellie came home from school and saw me sitting in the kitchen with her mother and heard that I had come from Collingwood short-term care unit she immediately became very upset and said 'No. No go there, no more, not now'.

Although it was sometimes quite easy to get answers from the children regarding whether they had enjoyed their play activities and wanted to go to the units again, it was very difficult to obtain any understanding of what they thought about being absent from their families and home. However, the remarks of the following two boys suggest that some children have an awareness of loss when experiencing short-term care. For example, 13 year old Duncan MacKie was having a week away in a hostel and every morning when he arrived in school he would say to his teacher, 'I'm missing my Mum, do you think she's missing me?'. And 12 year old Gareth Evans returned home after two weeks away in a hostel and was overjoyed and surprised to find that his pet rabbit still existed. The next morning when he got to school he said to his teacher, 'And my rabbit was *still* there'. His words were perhaps an indication that he had felt his absence from home had been an experience of great loss: it was with surprise and relief that he found again the pet rabbit which had inexplicably disappeared from his life for two weeks. Little is understood about how children with grave intellectual handicaps actually perceive their absence from home and explain their loss to themselves. For some of them, short-term care probably seems like a recurrent bereavement. For this reason the arrangement should not be lightly embarked upon or recommended as always good for all children.

It is no wonder that parents deny the homesickness and any ill-effects that the separation might have on their children, for they receive no guidance in coping with this painful fact. Mrs Adams, the mother of five year old Clara, described her daughter as being very aware of the separation and herself as in a dilemma about how to cope with it.

> 'I try to tell her beforehand when she is going but she then keeps trying to make me say she is *not* going after all. It is very difficult

> because the comfort that she wants and is asking for, I cannot give her. I have to be honest with her and I cannot pretend that she is not going just to keep her quiet. Sometimes when I take her to the hostel she tries to find an excuse to keep me there. Her favourite thing is that she wants to go to the loo and then she keeps me in there with her, not doing anything in the loo but knowing that I would not go off and leave her alone there in case she fell. Dad won't take her anymore, she got upset and that upset *him*. When we fetch her she bursts out crying when she sees us and immediately says "Goodbye everybody". On the first night back she always asks me "Will I see you in the morning Mummy?". And she always clings for the first few days when she is back. She likes to see me all the time and even follows me to the loo and I have to keep the door open when I am in there. I've never had any help from the staff or the social worker about these worries.'

Mrs Farley described how she felt when she first recognised her six year old daughter's homesickness:

> 'When Elaine stayed for one night she seemed OK, but when she stayed two nights she had a queer reaction. She was alright in the car going home but soon after getting indoors she became very distressed and clung to me, crying and angry for about an hour.'

Mrs Farley found this behaviour very difficult and upsetting and she concluded that it was because her little girl had been missing her. One day, a few weeks later, Mrs Farley was visiting a friend whose seven year old mentally handicapped son was also having occasional short-term care, and she noticed him reacting in the same distressed way when he returned from the hostel. She said:

> 'The expression on *his* face was exactly like when Elaine made a fuss. I felt terrible inside when I saw him do it. I felt like crying. I wondered whether I should tell his mother what Elaine did when she came back. His Mum didn't seem to notice any connection between what he was doing and him being away from her. In the end I never said anything to her. But I felt like crying for both of them, him and Elaine. It came over me then that the children must suffer a lot when they are away, but nobody ever admits this.'

Mrs Adams and Mrs Farley were not the only parents who said that homesickness had long worried them; but they had never admitted it and none of the professionals had ever spoken to them about it.

Parents were sometimes very puzzled about their children's reactions to short-term care. They did not know whether they should have suddenly or very gradually introduced the separation, whether they should have visited them when they were away, whether they should always expect some after-effects, and what exactly these might be and how they should handle them.

It appeared that mentally handicapped children's reactions to short-term care (which for children without handicaps would have been understood as the normal reactions to a separation experience) were often dismissed by professionals as a manifestation of their mental handicaps, or due to a deterioration in their condition, or the result of poor handling by their parents. Disturbed and anxious behaviour such as bed-wetting, wakeful nights, clinging, following parents around the house, was rarely considered as a normal reaction to short-term care. And the parents were not warned to expect anxiety reactions nor given any advice about how to respond to the unhappy behaviour.

Mr and Mrs Jepson let their two year old celebral palsied son go into short-term care for a month because Mrs Jepson needed a prolonged stay in hospital when she was expecting her second child. The staff told his parents that it was not necessary to visit him every day, but they decided to do so. For the first few days he was there both parents had visited him, and after the mother went into hospital, Mr Jepson had done so on his own. He went every evening and, because the little boy cried so much when he tried to leave, he always stayed with him until he went to sleep. When Charles returned home they found him 'different and difficult' and then they began to torment themselves by thinking that his disturbed behaviour was their fault because they had ignored the staff advice to keep away.

Mrs Jepson said:

> 'When he came home he was clinging and did not want dad out of his sight, and he started playing us up one against the other. He seemed jealous of us together and of the baby. Sometimes he would not let dad go out of the house or go to bed in the day after coming off night-duty. He would make a fuss and start crying on the landing when dad shut the bedroom door. He would hold his breath and then laugh when dad came out of the bedroom and picked him up.'

The parents went to their doctor and asked for help, and an educational psychologist came to see them. He advised them to ignore the undesirable behaviour and they were relieved to find that Charles gradually settled down again. However, nobody ever suggested that the behaviour was probably the result of normal anxiety caused by the separation experience and then arriving home to find a new baby.

They believed they were at fault, for having visited him every day when he was having short-term care. Nobody reassured them that their visits had probably prevented Charles developing even more unhappy behaviour.

These very caring young parents were typical of many who did not have any background knowledge about the effects of separation on young children, but wanted to do what was best, and needed advice and reassurance that it was right to visit and maintain contact when their children were having several weeks' short-term care.

The likely bad effects of short-term care on young children was not receiving sufficient attention in any of the facilities visited during the study; indeed, the professionals employed to organise the separation of the children from their parents seemed to be surprisingly ill-informed and insensitive to the stress that might be caused by the experience. It was as if the work of John Bowlby[2] had never been published, the Platt Committee[3] recommendations had never been drawn up, or the James Robertson[4] films on young children in nurseries and hospitals had never been made.

The majority of parents and care staff are not receiving any advice on how they should respond to children who are upset about having short-term care. Some maintain that the children are not at all upset by it. Others recognise that there is some stress but believe that this can be avoided if they are kept in ignorance about *when* they are going. So, in some instances, the children are having their cases smuggled onto school buses without their knowledge, and they are being given the wrong information about when and where they are going, and parents are asking teachers to break the news to them when they get to school. All this secrecy must surely increase their feelings of insecurity.

The parents of seven year old Ned Tomson were very aware that he was upset about going to the hostel, but they could not agree about the best way to organise his admission, and they had no advice about their problem; indeed, the social worker and care staff seemed unaware of their worries. Due to his unhappiness about going away his parents decided, on the third time he went to the hostel, that they would get his case ready without him knowing, and then say that they were going for a drive, and when he was at the front door ready to go out, his mother would say 'What about your case then?' and go upstairs to get it. But this plan upset him dreadfully and his mother said that they would never do it like that again and they had only done it then because a neighbour had suggested it. Mrs Tomson now thought it was best to smuggle out his case to the car without him knowing and then drive to the hostel without any explanation, although he made a fuss when he actually arrived there. Mr Tomson, however, favoured complete honesty and thought it was better for Ned if they talked about his going away and let him help with packing his case and putting it into the car.

As neither parent could agree which was the best method of getting him to the hostel, they sometimes took him by one method and sometimes the other. But, whatever plan they followed to try and ease the situation, Ned always got upset when they arrived at the hostel and they always felt reluctant to leave him. The staff were aware of this reluctance, but insensitive to the confusion and unhappiness that lay behind it, and they merely said, 'The father needs encouraging to leave or he would never know when to go'.

Mrs Tomson described how if they were driving anywhere in the area of the hostel, on trips which had nothing to do with going in for short-term care, Ned would get very agitated when he recognised certain landmarks such as the roundabout and the traffic lights. It was obvious that he found short-term care a very traumatic experience. During the study it was noticed that his behaviour in the hostel was very tense:

> He was upset during the four days that he was in, crying and asking for his mummy and wanting to go home. His behaviour alternated between playing on his own at pushing cars up and down the room, or wanting to be cuddled, or staying on the edge of group play just watching and then suddenly rushing at the group and throwing all the game about. He got increasingly tense as the time went on and he saw more and more parents coming and going with their children. When his father arrived to fetch him he had just settled onto my lap for a session of group singing. He saw his father come through the door and was at him like a shot and into his arms instantly, saying 'Go home now, go home'. He ran to his case which was in the office and pulled it towards him and became very impatient when a member of the care staff had difficulty in shutting it properly. His father stopped to speak to me on the steps, but Ned kept pulling at him and saying 'Go home now, go home now'. He only said goodbye to the staff and the other children because his father insisted on him doing so. (Observation made during study.)

Care staff are not always aware of the reality and extent of children's homesickness. This may be due to their insensitivity to child stress, or to lack of knowledge or training about child behaviour, or to the organisation of the children's day which means that their care is fragmented between many different people and no one member of the staff ever sees the whole picture. This last point was made earlier (pages 164–165) with reference to Gwen Davies.

The following observation once again emphasises how fragmented care can prevent staff from noticing what is happening to individual children:

> Tina, aged six, is always uneasy. One day, when she was due out after a week in short-term care she got quite disturbed. She saw other parents coming to fetch their children, but she was not due to leave until later in the evening. During the afternoon and early evening it was not possible to go out of doors because the weather was bad, so the staff and the children settled down in the big sitting-room to various play activities. But Tina would not settle. She kept running to the front window to look out and see if her mother had arrived. 'Mummy come?' she kept saying to herself. She was also observed going at least four times to each one of the eight staff on duty and asking the question 'Mummy come, go home?'. The staff responded with kind reassuring words: 'Yes, soon', and 'In a little while'. She would then walk away and go to the window and again ask herself the same question. (Observation made during study.)

The observations of Tina, like those of Gwen, gave a whole picture of a very homesick little girl. But the staff perception of her homesickness was minimal because their picture of her was fragmented. If any one member of staff had been asked how many times Tina had asked them the question 'Mummy come?', he or she would probably have recollected that she had asked it two or three times and they may have noticed her running to the window. But if *all* members of staff had *recorded and added up* exactly how many times she had asked the question, the total would have been at least 30 times in the course of approximately two hours, as there were eight care staff on duty (six care staff and two domestic staff). She also asked me the question persistently, and all the parents who arrived, and some of the older children and a volunteer who was present. With the addition of these other people, the total number of times she asked the question within the two hour period would have amounted to approximately 80 or 90 times – an almost non-stop anxious repetition of the same question. But individual members of the care staff, because they were busy and unable to make sustained observations of the little girl, did not realise that she was really very homesick and all her activities were a restless seeking of clues about her mother's arrival. When Tina's parents did arrive she was very clinging and weepy, but the care staff reassured her mother that she had been 'Quite happy, looking out for you to come'.

The following observations of five year old Ben, are a further illustration of how only *part* of a child's stress may be seen by each of the adults involved in his care—teachers, care staff, bus escorts, parents—so the *total amount of stress is always under-estimated.* And the social workers who arrange the short-term care are not likely to witness *any* of the child's stress:

> Ben, Delroy and Jessie all aged five, were going into short-term care together for one night's stay. The three children were friends and in the same class, so their parents, the teacher and the care staff collaborated in booking them in together for short-term care because they thought that this would be nicer for them.
>
> I went to the classroom to be with the children during the last half of the afternoon and to travel with them in the coach to the hostel. I had earlier been told by Ben's teacher that he was always anxious about going for short-term care, in spite of the fact that he was going with Delroy and Jessie. 'On the days when he goes to the hostel he keeps on and on asking me "I'm going home today?"', the teacher said.
>
> When I arrived in their classroom all the children had been making cakes and the teacher and her assistant were talking about taking little bags of cakes home for 'Mummy and daddy's supper'. The three children who were going to the hostel for the night were told that they could put their bags of cakes into their cases for 'Peg and Jim' (the hostel staff).
>
> Ben began to get very anxious and fidgety as it got nearer the time for school to finish. He kept staring at the door and would not listen to the story or sing the little song the rest of the class were singing before they went home.
>
> Ben began to cry as the noise of the school buses and the voices of the escorts and other children were clearly heard from the school entrance hall. His teacher took his case and his teddy bear from the cupboard and tried to comfort him by saying 'Look at teddy, he is going with you too. What is his name?' But Ben would not be comforted and he pushed the teddy to the floor. He cried more and more and looked very shrivelled. He watched apathetically as the teacher put a little bag of cakes into his case.
>
> The teacher then tried to cuddle Ben but he stiffened up. Delroy came over and stared at Ben and picked up the teddy from the floor and cuddled it. Then Delroy put down the teddy and picked up his own case and marched around the room with it, waving his hand and smiling. He stopped by Ben and stared closely into his face with an expression of sympathy and puzzlement. His happy marching around the room with his case had not succeeded in cheering up Ben. He sat bleakly in the teacher's arms.
>
> Ben suddenly heard a bus revving up and called out 'Bus, Bus' and cried some more. Jessie came and sat down by him and stared at

him, then she went to her case, picked it up and brought it back and sat down and held it on her lap, still staring at Ben. Jessie did not look unhappy.

The teacher then opened Ben's case and took out his things and looked at them and held them up and talked about them to him.

'Here's your flannel.'

'Flannel' repeated Ben tearfully.

'Oh, and what's this?', holding up his pyjamas. He was silent.

'Pyjamas, Ben?' she asked smiling.

'Pyjamas' said Ben, he now began to smile himself.

With the teacher's encouragement he seemed to be cheering up.

Then, all of a sudden, the escort from the school bus that generally took him to his home came into the classroom, but she did not take him out because he had got to wait for the bus going in the direction of the hostel. He was very upset when he saw her taking the small group of regular children she always took home in 'his' bus.

He became very distraught as the door closed behind her and the little group of children she was taking on her bus. Perhaps he was thinking he would never get back to his mum again. Nobody can guess the stress and confusion which probably occurs in a five year old child's mind when he is ignored by the escort who usually takes him by the hand and says 'Home to mummy' to him.

When Ben was taken out by an escort he did not know and put onto the bus going to the hostel, he was very quiet and weepy. He did not speak on the journey. When the bus turned into the hostel drive Ben put his head down and sobbed a lot. Entering the hostel he walked around and around in a circle in the big sitting room, crying and looking very saddened; then he stood for ten minutes in the area by the big windows where he could see the buses and taxis going away. After the last bus went out of the gate he walked in circles crying for approximately 15 minutes.

A member of the care staff tried to comfort Ben and attempted to get him to cuddle his teddy bear, but he flung it down. Delroy went to him and patted him and followed him around, but he took no notice. Delroy picked up the discarded teddy and cuddled it himself. Another member of staff went to Ben and led him to his bedroom and showed him his bed and chatted to him. This seemed to calm him down and he then came out from the bedroom and joined in the group watching the television. In the meantime Delroy and Jessie sat together in a big armchair looking at comics and television.

Ben remained very subdued for the evening, but a member of the care staff said that after he went to bed in the room which he shared with another child, the two small boys were heard chatting together and he was apparently happier.

> In the morning Ben looked very cheerful as he said goodbye to the staff and set off back to school on the bus with Delroy and Jessie. (Observation made during study.)

The above three children had similar family backgrounds, the same teacher and the same method of going to the hostel. Delroy and Jessie did not seem unduly disturbed by the experience, but Ben had been disconsolate. For him, it was obvious that a cycle of stress had been caused by the way in which his admission had been arranged. An experience of being apparently forgotten and left behind by a familiar bus driver and escort would have been upsetting for any child, handicapped or otherwise, but for a young handicapped child with difficulties in verbal understanding and perception of time and place, the experience must have been quite devastating and must have caused terrible feelings of insecurity before he ever arrived at the short-term care facility.

Sadly, what happened to Ben is all too common. It happens because many of the professionals who organise short-term care, and many of the parents who agree to it, have a blind faith in the popular idea that it is always good to separate a handicapped child from his family for short periods. This leads them to make arrangements which they would hesitate to make for children who are not handicapped. And in these arrangements there seems an implicit agreement that handicapped children do not have the same feelings as ordinary children and therefore will not suffer stress through separation and strange experiences.

In the sort of situation that Ben faced with such trembling and uncertainty, there is a steady build up of stress through a series of quite frightening events throughout the day: the child has his case put on the school bus when he leaves home in the morning, he sees it unloaded at school, he is at school all day with it in the corner of the room or in the teacher's cupboard, if he can see it he is constantly reminded that he is going away after school, if he cannot see it he may worry about where it has gone; he hears the school buses arriving to take everyone home at the end of the school day but he is left behind when his usual group goes on to his bus; he is put on an unfamiliar bus and goes off in another direction with a strange driver and escort and different children; or he may go on his familiar bus but it will pass the end of his street or even his house and will not set him down as usual. Any one of these occurrences is enough to make a young child deeply anxious.

It is essential for anyone organising short-term care to bear in mind that individual children may suffer overwhelming anxieties about the arrangements, which may not be noticed by anyone at all because the children pass through the hands of many people during the course of a day. Methods of admission should be carefully considered and regularly reassessed, and at no time should any decision be taken about a handicapped child that would not be considered right for an ordinary child. And the age and the particular needs of each individual child should always take precedence over administrative convenience.

Social workers who are responsible for short-term care admissions sometimes seem unaware that the separation should be organised in a way that does not upset the children. This is probably because they sometimes become over-occupied with placing numbers of children in numbers of beds and fail to look at individual needs, methods of admission, quality of care and the effects of separation. The failure of social workers to consider the appropriateness of the facility they recommend, and its quality and effects, may also be due to the poor image they have of mentally handicapped children. The notes of one social worker described a cerebral palsied child as 'a permanent pudding' and another wrote of a boy with Down's syndrome as 'a lump of a mongol'. Professionals who have such negative opinions of mentally handicapped children are not likely to support the direct care staff and the parents in recognising and helping the children's normal homesickness. (See also pages 76, 136, 137 and 142 for some other references to images of handicapped children.)

It might be helpful if all the professionals responsible for planning and providing short-term care could start from the assumption that the experience is likely to be very traumatic and even harmful, rather than from the assumption that it is always good and will not affect the children. An acknowledgement that it may be harmful could be one way of setting standards and concentrating on the needs of the individual child.

Reference was made in Chapter 5 to the variation between parents' and professionals' perception of services. Variations also exist regarding parents' and professionals' perceptions of the children's reactions to the experience of short-term care. Fifteen year old Diane North's parents described her as 'very unhappy' when she was away. 'It was obvious' they said, 'she was tearstained and miserable'. But in a doctor's notes about her stay, in which he recommended that 'She should have regular periods away from home', she was described as 'having a very happy stay'. Senior professionals who are responsible for writing up the children's notes and making recommendations on their future care may never have an opportunity to observe their unhappy reactions to the recommendations; so on the one hand the children's stress is being denied by care staff and parents who find it too painful to openly admit, and on the other hand it is being denied by senior professionals who may be ignorant about the effects of their recommendations because they do not see the children when they are actually in the residential care facility.

Mrs King (see also page 101) spoke of how a doctor wanted her blind, multiply handicapped daughter, Lara, to have short-term care in a mental handicap hospital when she was two years old. Her parents were eventually persuaded to let her go into Moor Grange Hospital but they were very distressed about the poor care she received and did not let her go there again. Explaining how she agreed to let her go to such an unsuitable place, Mrs King said:

> 'When I protested to the doctor and said Lara would not like it there, he told me that she was too handicapped to be aware of *where* she was so it did not matter where she went. "But she has feelings" I told him. The doctor did not seem to think she had any feelings at all, and kept on and on to me about letting her go to Moor Grange and how she wouldn't know anything about it. So in the end I let her go. I felt I ought to obey. I did as I was told in the end. And I let her go and did not ring them up or worry them about her. But it was terrible. We could not enjoy ourselves knowing that she was in such a horrible place.'

When placing multiply handicapped children in short-term care it is extremely unjust to assume, as did Lara King's doctor, that because they are blind and deaf and immobile they will be unaffected by the loss of familiar surroundings and people. They may suffer immense grief and bereavement which is made worse because they lack the hearing, sight, language and mobility which could give them clues to what has happened. Removal to a strange environment will be a total dislocation of the profoundly handicapped child's world because it deprives him of all the detailed points of reference which mean security. The child at home may spend a lot of time lying on a settee, knowing the security of familiar sounds, touch and smell, the slant of light from a particular window, the sound of voices, the position of the television and the fire, neighbours who come in, the pet dog, cat or bird, the sounds coming from the kitchen and upstairs – all these details are vital and all disappear when the child goes away for short-term care. If he goes to a short-term foster family, where the overall home environment is basically similar to his own home, the loss may not be so devastating as going to a hostel or hospital where the lighting, smells, room size, acoustics, furniture and floor covering are not a bit like an ordinary family home, and where the many people coming and going can be confusing and frightening. (The reactions of profoundly handicapped children to short-term care have also been referred to on pages 152 and 159–160.)

Professionals who are distant from the daily care of the children (planners, social workers, doctors and psychologists in particular), tend to have a very sanguine view of the services they plan and recommend, because they are not likely to witness and realise the extent of the children's homesickness. But how do the direct care staff cope with the problems of child stress which daily confronts them? How do they help the parents and the children, and each other, and ensure that short-term care is more than just a crude separation service? It was disquieting to find that homesickness was rarely recognised as a sad and normal state about which some action can and should be taken. None of the facilities had a written policy about how to recognise and cope with homesickness, giving advice to care staff on such basic child oriented actions such as cuddling the children, keeping familiar articles around them, letting parents stay, keeping them in their own clothes, having child/staff assignment, making sure that home toys were retained, getting to know about home routines and then *keeping* to them, using familiar language and jingles, and respecting parents' methods of feeding, dressing and toileting. None of the facilities had attempted to define homesickness as anything beyond 'a little fretting and crying'; it was not seen as a condition which could affect sleeping, eating, play and social behaviour, nor as a problem which merited staff meetings and discussion. If it was recognised at all it was generally alluded to in the following terms:

'A nuisance and just attention seeking.'

'Upsetting for parents to see.'

'Upsetting for other children, will set them all off.'

'Put on'—the child really being 'very settled and happy'.

'Unreasonable' because the facility was 'very nice and the staff were taking a lot of trouble to make things happy'.

'Preventing the child from enjoying the nice things that we (the staff) are organising, such as walks and play'.

Part of being 'subnormal'—'a normal child would not make such a fuss'.

'Spoilt'—due to parents' 'bad handling'—'short-term care will cure this spoilt behaviour'.

'Selfish'—'not wanting their parents to have a break from them'.

The following sparse report of one small child's reaction to her first day in short-term care illustrates the attitude of one member of care staff to a child's misery; there was an awareness of the child's homesickness but a paucity of positive ideas about what could be done to remedy matters:

> 'Rather a miserable child; very aware that she is not in her own home. Calls "Mummy, Mummy" constantly. We found it best to sit her on the floor where she can see all that is going on but not talk to her or take any notice of her, then she stops crying. Slept very well and ate a small amount.' (Report by care staff on a five year old, cerebral palsied child receiving short-term care for the first time.)

As mentioned on page 171, there are several reasons why care staff may deny the children's homesickness. Perhaps they lack training and experience in picking up signs of child stress, or they are too busy to notice what is happening, or they do not believe that mentally handicapped children have the same feelings as other children, or they think that the parents' need for a break is more important than the feelings of the children. Perhaps some staff, through years of working in residential care and hospitals, have learnt to harden themselves to children's sadness; others might deny the sadness because they are themselves upset by it and to deny its existence is one way of coping with their own feelings. Whatever the reason for not acknowledging that handicapped children are subject to homesickness in the same way as other children, the staff working in short-term care facilities should have opportunities to define and discuss the problem and draw up some ideas on how they are going to cope with it. Concurrent with this is the need for care staff to have inservice training on child development.

Does short-term care cause harm?

Short-term care is often said to be a means of preventing or delaying long-term care, but I would suggest that if it is badly done—if the children's stress is neglected, their routines upset and their homesickness not comforted—this can result in the initial problems of their handicaps being overlaid with additional problems caused by the effects of the separation. This accumulation of problems may well make them more difficult for their parents to manage and inevitably cause them to drift into long-term residential care. Some parents find their children starting to bed-wet after short-term care, or regressing in their behaviour and having disturbed nights and demanding attention. Such reactions after an experience of separation are normal for any child, with or without a handicap, and should be expected after a child has short-term care. However, when mentally handicapped children have these problems after coming home from short-term care the behaviour is not usually regarded as a normal reaction to their having had a separation experience, but construed as a manifestation of their mental handicap. The child may then be considered as getting even more difficult and impossible to manage, and this may influence the question of whether long-term care is needed, and *then* prejudice a decision to permanently separate the child from the family. (See pages 42, 106–107 for other references to children drifting into long-term care.)

A more detailed examination than was possible in this report, into the effects of short-term care on vulnerable children, would probably disclose worrying aspects which would cast very grave doubts on the whole philosophy of the service and its present organisation. A letter from a regional medical officer, addressed to Exodus (the pressure group campaigning for the discharge of all children from long-stay hospitals), disclosed that in one regional health authority there were approximately 140 children of all ages living permanently in long-stay mental hospitals after having been initially admitted for short-term care periods.* The following children are only three amongst many who raise suspicions that poor quality short-term care is likely to precipitate long-term care; each of the three went into a busy over-crowded mental handicap hospital for their short-term care periods and each is now living permanently in the hospital.

> Sabu, now aged 11, had 12 short-term care admissions between the ages of five and seven years old. Each admission was for one month. At the age of seven he was admitted for long-term care.
>
> Martina, now aged 13, had ten short-term care admissions between the ages of four and six years old. Each period was for one month. At the age of seven she became long-term in the ward.
>
> Janet, now aged 14, had 16 short-term care admissions between the ages of four and seven years, each admission lasting for three to four weeks. She became long-term in the ward at the age of seven.

Did Sabu, Martina and Janet and many other children, and a high proportion of the 14 630† young people aged 20 to 34 years old who are now permanently in long-stay hospitals, become long-stay because of poor quality short-term care which ultimately did them more harm than good?

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* Letter dated July 1982 to Peggy Jay, Chairman of Exodus, and referred to here with the permission of Peggy Jay.

† This is the approximate figure for 1980, kindly supplied by the staff of the DHSS Statistics Department.

Summary and conclusions

The description of children in this chapter suggests that short-term care is a very dubious service which had never been thought through in terms of good practices in child care. It is too often considered the answer to all family problems, but in reality it may be responsible for creating more problems.

Its faults lie in the fact that it has not been developed from any firm child-care principles and aims. In the last ten years it has been expanding far too rapidly and, in the absence of any other form of family support, it has acquired a reputation for helping families which is really founded on very little concrete evidence. Indeed, the findings in this report would suggest that: first, the children who use short-term care are frequently distressed by the experience; second, their families are left feeling very ambivalent about whether it is really helping; and third, the professionals who plan and provide the service are not looking at it from the viewpoint of the child. To subject any child to constant changes of environment and recurrent experiences of loss of family is definitely not in line with the principles which have come to be regarded as essential to the care and upbringing of children since the passing of the first Children's Act in 1948. It cannot be emphasised too strongly that short-term care services are, at present, so badly organised that the children are likely to be harmed by the experience.

Three of the main recommendations of this report, highlighted by this chapter about the children, are:

1. *short-term care should be regarded as a very specialist service needing clearly defined aims based on principles of child care practice and requiring careful continuous monitoring of standards with an emphasis on how it may be affecting individual children;*

2. *no child should be given short-term care unless the decision has been considered very carefully in terms of that particular child's individual needs;*

3. *every child's use of short-term care, once started, should be regularly reviewed to consider whether the pattern of use is likely to be harmful.*

References

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3 Great Britain, Ministry of Health. The welfare of children in hospital: report of the committee. (Chairman, Sir Harry Platt.) London, HMSO, 1959.

4 Robertson, James. A two-year-old goes to hospital (1953). Going to hospital with mother (1958). Kate (1967). Jane (1968). John (1969). Films available from Concord Films Council, 201 Felixstowe Road, Ipswich, Suffolk.

Charting children's grief caused by the experience of short-term care

A *Some ways in which children express their stress and anxiety when in short-term care (observed during study)*

1 *Purposeful physical activity (searching behaviour, seeking the mother/father)*: running to the doors and windows, trying to open doors and windows, wanting to go upstairs, into the kitchen or office or garden, preparing to leave—wanting to pack case.

2 *Apparently purposeless physical activity (bewilderment behaviour)*: milling aimlessly, rummaging in cupboards and toy boxes, plucking at clothes, buttons, cuffs, hankies, wringing hands, winding curtains around selves, continuous crying.

3 *Clinging to people (comfort seeking behaviour)*: holding on to staff, clutching at their legs, feet, hands, arms, clothes, as they pass, following staff into staffroom and office, wanting to be picked up and cuddled, wanting to sit on laps.

4 *Asking questions (reassurance seeking behaviour)*: repeatedly asking anxious questions such as 'mummy come?', 'go home?', 'car?', 'only one more night', 'daddy coming?'.

5 *Quarrelsomeness (protest behaviour)*: competing for staff attention, upsetting games, tipping over food and drinks, pushing chairs over, shouting and crying when approached by other children, initiating a quarrel and then looking towards staff for intervention, pinching and slapping and pushing other children.

6 *Withdrawal (mourning behaviour)*: silent crying, rejection of food and drink, standing staring out of windows, standing silently staring at staff and other children, refusal to join in games, lying on the floor in an abject posture, sitting in corners of the room, curling up in chairs or settees and shrinking back when approached by staff or other children, not speaking.

7 *Loss of abilities (characteristic of anxiety and grief)*: dribbling, loss of verbal ability, loss of concentration, incontinence, inability to swallow food or drink, loss of ability to dress or wash self.

(All children experiencing separation and loss through short-term care may show any or all of these signs of grief during their stay. Children with cerebral palsy and allied multiple disabilities may be especially prone to the signs listed in 3, 6 and 7.)

B *Some reasons for staff apparently not recognising children's grief*

1 *They find it painful to acknowledge the children's grief*: staff feel saddened when they witness grieving children, and they are not sure how to help them so they deny the grief.

2 *They lack training and knowledge about normal child behaviour and development*: everything the children do is considered to be due to their mental handicaps, therefore their normal grief reactions are never recognised. They think the homesickness is only temporary and not very important ('they will soon settle').

3 *The organisation of staff time and the children's care*: frequent changes of staff, and task allocation instead of child assignment, causes fragmented care. This prevents opportunities for observing and building relationships with children; no one member of staff will ever see the whole picture for any one child.

4 *Staff inability to be self-critical*: they lack the confidence to be self-critical; they are over-confident about the basic aim of short-term care (that is, to separate is good); they have never received firm guidance from seniors in defining child-oriented aims and guidelines.

5 *Lack of contact with parents*: staff and parents are failing to recognise and share together the knowledge that children are having bad reactions to short-term care; staff and parents may unconsciously collude in denying the children's grief.

C *Some reactions of children when they return home (described by parents)*

1 *Withdrawn behaviour:* quiet; avoiding eye contact; not smiling; very passive; stiffening when picked up and cuddled; not talking so much.

2 *Anxiety behaviour*: following parents around the house; not wanting parents out of sight; twiddling with clothes, buttons, hankies, hair, fingers; frightened of going to bed; worried when on journeys or shopping or visiting friends and relatives; wanting to be cuddled, carried about, lifted up; constant questions about when going away again; weepiness; disturbed sleep, nightmares; quarrelling with siblings; uncontrolled giggling and excitement.

3 *Loss of skills*: bed-wetting, incontinence during the day; loss of ability to feed or dress or wash self; loss of mobility; loss of verbal ability; poorer concentration; dribbling.

(Parents referred to children behaving in these ways after returning home from short-term care. The behaviour could last for anything from one day to several weeks.)

D *Some reasons for parents denying their children's grief*

1 Recognition is too painful.

2 They need support, and fear to admit that it is upsetting their children in case there is nothing else available for them.

3 They lack experience of normal children and believe that the disturbed behaviour is due to the mental handicap.

4 They think the upset is only temporary and does not matter very much ('they will soon settle').

5 They have been pressurised into using the service and are timid of voicing their misgivings about its effect on the children.

6 They lack contact with staff and opportunities to discuss their children's reactions; parents unconsciously collude with staff in denying the children's grief.

7 The task for staff: setting standards

The staffing of short-term residential care facilities between 1977 and 1981 when this research was taking place, has to be seen against a background of three major influences.

First, there was the growing enthusiasm for community care from the mid 1970s onwards (see Chapter 1) and the emergence of the idea that short-term care was going to be a valuable new form of family support. Instead of being merely an appendage of long-term services, it was suddenly becoming an important service in its own right. The problem for the staff was that they had to find themselves as workers in this new service. They needed to decide their aims and define the principles of short-term care. But, sadly, one of the main findings of this research was that short-term care staff have never received enough guidance in deciding their aims, principles and standards. That lack of guidance resulted in the poor practices described throughout this report.

Second, the threat of unemployment was bringing into residential care work a variety of young people who might otherwise never have thought of taking jobs in residential care services; some had degrees and diplomas in teaching, social work, psychology, the arts, social administration, design, advertising and commerce. Never before had so many people with such varied qualifications and higher education taken jobs in residential care services and wanted to stay. Some were staying because there was only the prospect of prolonged unemployment if they left. Others were staying because they found that they liked the work and they hoped to take further training later on for working with mentally handicapped children. In one short-term care facility, the 19 staff included three qualified teachers straight from college, an arts graduate and another with a degree in social administration, as well as mental handicap nurses and staff with NNEB qualifications; and there had not been a vacancy on the staff for more than a year.

Third, there was the long-protracted publication of the Jay committee report[1] and rumours that it was going to abolish mental handicap nurse training and threaten the future of those who were already qualified and working in hospitals. Some nurses decided that mental handicap hospitals were doomed ships and that it would be wise to move out into community care. And young people who had planned to train as mental handicap nurses decided to wait for a while and get jobs in community facilities and perhaps do an NNEB* or CSS† training instead. Short-term care facilities provided popular employment for these people seeking experience, job security and a future career with mentally handicapped children in the community. So, in addition to describing a new model of care, an unexpected spin-off of the Jay committee report was the shake-up that it gave traditional services and the unsettled feelings it caused which, although difficult at the time, enabled long-established forms of training and care to be looked at very critically and gave encouragement to forward-looking nurses who were interested in developing community care services.

Thus, during the latter half of the 1970s, the staff of short-term residential care facilities in the community (hostels and homes run by local authorities and health authorities and voluntary organisations) consisted of a mixture of: inexperienced but well-educated young people who had been drawn into residential care work because of unemployment; experienced and qualified mental handicap nurses who had long worked in mental handicap hospitals and now wanted to work in the community, partly because they wondered how the Jay report might affect their hospital careers and partly because a job in the community promised to be more satisfying than one in a hospital; and young people who wanted to work with mentally handicapped children but were not yet sure what training they should be taking because they, too, were waiting for the Jay report; there were also older married women coming back to work after their children had grown up, some of whom were qualified mental handicap nurses or nursery nurses and some unqualified but experienced with children because of bringing up their own. In mental handicap hospitals the staff consisted, as always, of qualified nurses and nursing assistants; amongst the latter were an increasing number of young people with higher education and various qualifications who had become nursing assistants rather than be unemployed.

The mix of staff, whether in community facilities or in mental handicap hospitals, brought varied enthusiasms, experiences, aspirations and expectations to the care of mentally handicapped children. Such a mix might have seemed ideal, but their senior managers all too often failed to make use of staff capabilities. And because short-term residential care was such a new service, having grown out of nothing more than a good will to help families and not having any firm base in principles of child care, it was easy for poor care and bad practices to creep in and take root unnoticed.

The contents of Chapters 3 to 6 might suggest that the staff of

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*NNEB = Nursery Nurse Education Board qualification.

†CSS = Certificate in Social Service.

short-term residential care facilities are insensitive to the needs of children and parents. This was certainly true in a few of the places which were visited during the research, but poor care in the majority was *a symptom of lack of guidance from senior staff* rather than evidence of insensitivity or wilful neglect by direct care staff. The care staff were just not getting adequate opportunity for discussion about their task, nor did they have inservice training which was appropriate to this very new service. *In none of the facilities visited did the staff have clearly defined guidelines, written out for them to refer to, on how to care for children who were having recurrent short periods away from home.* And, all too frequently, the staff at all levels fell into the trap of judging the success of their short-term care facility by the numbers of beds kept filled, rather than by the quality of the children's care. Senior managers, as well as direct care staff, seemed to be drifting along, as if assuming that the setting up of a short-term care facility was in itself the task completed.

But it has not been enough to merely open a unit, gather together a group of staff, and then expect them to be able to run a successful short-term care service on the strength of their previous training and education or their experience in bringing up their own families or working in traditional long-term care services. Short-term care is a new service, throwing up new problems and making unusual demands on its staff. It seems, indeed, almost as if the staff of short-term care units are a *new profession*, their previous knowledge about mental handicap, children and residential care not always being sufficient to guide them through the special difficulties of providing this unusual type of care. It is the failure of senior managers to recognise the very special problems of staff providing short-term care that has caused the many difficulties and deficiencies which have been described in this report.

There was a feeling of almost euphoric hopefulness and excitement in many of the short-term care facilities which were visited during the research, especially in the newly set up units which had been either purpose-built or were upgraded long-stay buildings. A sense of achievement was implicit in the conversation of planners, managers and care staff, as if all were infected with excitement at starting a new service. The words of one mental handicap nurse expressed a very common feeling:

> 'At last I've got away from the mental handicap hospital and I am out in the community in a new unit and can run things as I wish.'

She had been appointed to be in charge of a new short-term care unit which the health authority had recently opened in an ordinary house in the middle of a town. Short-term care had previously been provided in a mental handicap hospital 15 miles away, and all the staff and planners were excited at having opened a unit to help parents and children in the community, and this sister-in-charge was looking forward to a professional independence that had not been possible during the ten years she had spent working in the hospital.

An absence of trepidation about the task of providing short-term care was a characteristic feature of its planning in the late 70s. In fact, the word euphoria, used above, well describes the atmosphere of the time. With many health and local authorities talking about setting up their own facilities, the bandwagon of short-term care was gathering momentum, but without enough thought being given to the children or their parents or to the special task facing the care staff. Probably never before in the history of mental handicap services had anything been hailed with such enthusiasm, but with the staff left so ill-prepared and unsupported, as in the short-term care services which expanded from 1977 onwards. Staff guidance definitely did not keep pace with the enthusiasm for planning nor with the fruition of the plans.

The setting up of some sort of short-term care service seemed to be an end in itself and thereafter the units could, and did, drift along; the staff were without any guidance and, consequently, poor practices were creeping in and being accepted. Lack of advice, too rapid expansion, wasted opportunities to make the best use of good staff, created the situations brought to light by this report. The units were dangerously autonomous and there was a marked absence of *national advice* on how to develop and guide this service in its infancy.

At no time during the late 70s and early 80s, when short-term care was being talked about so much, and when facilities were being planned and opened, did any national body with an interest in mental handicap, children's services, and residential care, issue firm advice and guidelines to staff about how the service should be developed and how standards of care could, and should, be maintained. There was a notable silence on the subject from the DHSS and MENCAP and from the professional bodies with an interest in mentally handicapped people and residential child care standards; and silence, too, from the national committees set up to issue policy documents on health and social services matters affecting families and handicapped children, such as the Central Health Services Council (CHSC)*, the Children's Committee†, the National Development Group (NDG)** and the Central Council for Education and Training in Social Work

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*Disbanded 1980 (last meeting held April 1979).
†Disbanded 1981.
**Disbanded 1980.

(CCETSW). Indeed, references to short-term care all too often reiterated clichés which had grown from vague assumptions rather than facts. For example:

> 'The support available to families should include easy access to short-term residential care.'[2]
>
> 'We believe that an adequate system of planned short-term care is not only one of the most cost-effective initiatives that NHS and local authorities can undertake, since it can be a potent means of reducing pressure for long-term admission to residential care, but that it is also one of the best ways of giving families the support they badly need.'[3]
>
> 'The main aims for authorities should be to . . . support those looking after mentally handicapped people at home by providing day services and short-term residential care for training, relief and holiday purposes.'[4]
>
> 'Short-term residential and respite care should be available to all families. It should not be seen as a crisis service but as an essential component of ordinary family support services.'[5]

The above statements are typical of those made in the last few years by government and by statutory, voluntary and professional bodies concerning the development of residential short-term care services. There has been no mention of child care practices, homesickness, or inservice training for the care staff to ensure that the needs of children suffering a separation experience would be given attention. In 1977, the National Development Group issued a special pamphlet about short-term care (*Residential Short-term Care for Mentally Handicapped People: Suggestions for Action*[6]), but this, too, failed to recognise the need for staff to receive firm guidelines on planning and practice. An attempt to monitor standards and give guidance on the development of all mental handicap services was made by the documents *Stamina*[7] (issued by the Royal Society for Mentally Handicapped Children and Adults) and *A Checklist of Standards*[8] (issued by the National Development Group); both these documents included references to short-term care, but neither succeeded in giving the guidance that was so badly needed by the staff and planners of this very new and rapidly developing service. The former document concentrated on the basic idea that short-term care should be available, and the latter suggested that standards could be monitored by a checklist of questions rather than by actual advice on what to do. A checklist of questions is an excellent way in which to promote critical discussion, but the staff in the new service of short-term care were still trying to find their aims and principles, and therefore they also needed to have some firm advice on exactly what they should be doing. The only document which came anywhere near to setting forth guidelines to staff on developing a philosophy of care based on clients' needs was that issued by the Personal Social Services Council* in their review of residential care[9]; this review was not specifically concerned with mentally handicapped children. Many of its recommendations and much of its discussion material applied to elderly people receiving residential care, but the document set forth a firm philosophy of care based on individual clients' needs which could be applied to any group of vulnerable people, whether they were elderly, mentally ill or mentally handicapped. This valuable review, however, was not apparently being used by staff who were planning short-term residential care services.

The material in Chapter 6 of this report suggests that the major problem facing care staff, planners, managers and other professionals (whether they are working for health authorities or local authority social services or for voluntary organisations) is how to provide short-term care services which will not only meet the needs of parents but will *also never lose sight of child care principles.* The findings showed that many of the professionals were disturbingly unaware of this being their major problem. This might have been because they were (albeit unconsciously) following the tradition of not considering mentally handicapped children as having the same needs as non-handicapped children. It might also have been because planners and senior managers were remote from the daily task of caring and did not know or see the children; and professionals on the periphery (for example, social workers, middle managers, psychologists, teachers, doctors and paramedics), were also distanced, having only passing knowledge of the daily task of caring and what it meant to the children themselves. Amongst the peripheral professionals it was the teachers who seemed to be most aware of the need for services to adhere to normal principles of child care, and they could cite examples of children showing disturbances after the separation experience; but very few teachers thought they had any responsibility to involve themselves in criticising standards of child care or suggesting changes. And the care staff, caught up in the emotional and physical pressures of their daily task, were getting few, if any, opportunities to stand back and assess their own work in the light of child care principles and to discuss this with their seniors or even amongst themselves.

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* Disbanded 1980.

In large hostels and wards (10, 15, 20 beds) the staff were inevitably developing poor habits of child care because of the pressures that were being put on them. The following list of staff tasks during a 13-hour period illustrates the pressures on care staff and how they are pulled in two directions as they dry to fulfil the dual task of looking after the children at the same time as giving the parents a good support service.

The demands made on care staff between 7 am and 8 pm in a 20-bedded short-term care social services hostel on a Wednesday during the week of the autumn school holidays.

There were five care staff on duty in the morning and six in the afternoon and evening. In the middle of the day, during the change-over period, there were 11 staff on the premises for 45 minutes. A part-time domestic staff member helped with the housework and did all the washing-up.

During those 13 hours:
at least a dozen families telephoned;
19 parents came in, to either pick-up a child, or to bring one in, or to make a future booking;
28 children were cared for during the day, aged from three to 13;
the children had a variety of disabilities and needs—16 could not dress, undress or wash themselves, 9 needed somebody to feed them, 7 were non-ambulant, 13 were speechless, 2 had behaviour problems.

The tasks of the care staff were:
feeding;
dressing;
undressing;
washing;
bathing the children;
taking the children to and from the lavatory;
getting children up and putting them to bed;
welcoming some children in and seeing others off;
organising play activities, indoors and out;
taking children for a walk to the corner shop;
talking to, and reading to, the children;
comforting younger, homesick children;
giving out medicines;
seeing to children's cuts and bruises;
making drinks and giving these out and helping some children to drink;
packing and unpacking cases;
making lists of clothes brought in;
checking lists of clothes going home;

making beds and changing bedlinen;
talking to parents;
answering the telephone;
doing bookings;
showing a prospective volunteer around;
housework—dusting, sweeping, ironing, washing, sewing on buttons and putting in a zip;
cooking breakfast, lunch and supper;
unpacking a delivery of groceries;
writing up the day's notes;
reading the notes of previous staff on duty.

The above list illustrates the immense daily pressures faced by care staff as they fulfil their tasks of home-making and child care. And, no matter how conscientious the care staff are, these pressures will inevitably put the children at risk of deteriorating standards of care, especially during the school holidays, and if the facility is large (ten or more beds).

But how much are the pressures and what may result from them fully appreciated by professionals on the periphery of the residential setting, and by the even more remote planners and senior managers (or even by the parents themselves)? Residential care workers seem to be a neglected group of professionals and the findings of this study would suggest that (a) their work-load in giving a residential care service should be regularly reassessed by managers, otherwise it creeps up and they will gradually take on more and more work, with the result that they will be unable to care for the children properly (this will apply in any residential setting, but especially in those with ten or more beds); (b) care staff should also have more opportunities for inservice training. Many of those met during this study had not been on an inservice training course for over two years, and some had never been on any courses. Many said 'We learn the job *on* the job'—a very dubious statement for any professional group to make about their work.

In conclusion, it seems that there are many parents using services which they do not really like, and they lack ideas or information about alternative types of care which might be provided. And many staff are getting what they call 'job satisfaction' from little more than the *idea* that they are helping parents. They live in a sort of professional pretence, or cul de sac, caught up with the basic idea that they are 'helping families' but not progressing beyond that fuzzy notion. It seems, indeed, that short-term care has failed because the notion of parent support has become all important and has superseded good practices in child care. Planners, managers and care staff have unfortunately tended to think of the children as the less important figures in the family support scene. However, the children are the *prime* figures and if they are not looked after properly, according to normal standards of child care, their parents are not going to be happy.

It is incredible that a whole new service for children should have emerged and expanded rapidly in the latter half of the 70s, receiving universal enthusiasm and approval, without anybody ever challenging the basic supposition upon which it is founded—that it is good to repeatedly separate handicapped children from their parents. The aim of this report has been to challenge the assumption that short-term care is always good and I hope the guidelines on the following pages will assist staff of all disciplines and at all levels to improve standards of service and face the task of providing future short-term care in a manner which will make it more than just a crude separation service.

Guidelines on providing and improving short-term residential care services for children who are mentally handicapped

Concerning philosophy, policy and planning

1. It should never be assumed that short-term residential care is always an ideal and major source of family support; other forms of help may be more appropriate for the child and his parents (for example, day care, a sitter-service, home helps).

2. Short-term residential care should never be offered as a palliative for family stress caused by problems of housing, unemployment or poverty. Ways of easing these problems should be sought rather than regarding the handicapped child as a major cause of the family's stress.

3. Parents should never be pressurised into using a residential service just because it is available. They may prefer some other form of help, such as a home help or a sitter in their own home. Their opinions should always be sought.

4. Professionals should never assume that the more handicapped a child is, the more relieved will be his parents about his absence from home.

5. Professionals of all disciplines and grades should beware of labelling the parents and their children and giving unjust stereotyped images of them.

6. The normality of parents being worried about separating from their children should be recognised by all disciplines and grades

of staff involved in planning and providing short-term care services.

7 The decision to take any child into short-term residential care, for no matter how short a time, should be carefully considered in respect of the child's needs and the effects that the experience might have on him, especially if he is a very young child. An alternative means of family support, such as a sitter, or the child going to a short-term fostering family, or the use of day care, should be considered before firm decisions about using a residential facility are taken.

8 The mixing of long-stay children and short-stay children in one residential facility should be questioned very carefully; it is difficult to meet the different needs of both groups of children and it is likely that problems will arise due to the loyalties of the staff being divided.

9 Short-term residential care services should always be local, within five miles of the children's homes.

10 The practice of admitting children to mental handicap hospitals for short-term care should be discontinued, as the environment of these hospitals is unsuitable for the care of children.

11 The practice of admitting handicapped children to paediatric and general hospitals for short-term 'social care' should be discontinued, as the environment of these hospitals is unsuitable for the care of children who are not sick or in need of active medical treatment.

12 All short-term residential care facilities should have a clearly defined written statement of their aims and philosophy. The statement should be drawn up jointly by parents who are using the unit and by staff of all levels. The statement should help to provide answers to such questions as 'Why is this child here?', 'What can we do for him?', 'Are we satisfied with what we are doing for him?', 'Are we meeting his needs, and if not, why not?' and 'Should he be here at all?'. Copies of the statement of aims and philosophy should be available to all parents and all members of staff. The statement should be critically reviewed each year, by parents and staff, to discover whether it is being followed and whether it is still applicable or needs to be changed.

13 The ways in which parents use short-term residential care should be carefully recorded and regularly discussed with them, to check whether their pattern of use suggests that their children are drifting into long-term care.

Concerning communication of information about short-term care

14 The way in which information about local short-term residential care facilities is disseminated should be regularly and critically examined by professionals and local parents' groups.

15 Leaflets about the short-term care facility are essential. They should describe the aims of the service, give a small picture of the premises, list the names of current staff, give the telephone number, explain how the service is organised and describe the pattern of the children's day.

16 The leaflets should not be expensively produced in large numbers when a facility opens; they will need to be occasionally updated because of staff leaving and aims changing, so it would be wiser to produce a limited number fairly cheaply and update them every year.

17 All parents should receive a leaflet and their opinions on its usefulness should be sought.

18 A one/two page newsheet should be issued every two months to parents and care staff and other professionals. It should give information on the development of the facility, its use, activities, changes of staff and other relevant items of interest.

19 One member of the care staff should be made accountable for seeing that parents have full information about the organisation of the short-term care facility before their child is admitted and throughout their subsequent use of the service. This member of staff might be known as 'parents' information officer'.

Concerning child care

20 Sending a child to several short-term residential care facilities is a bad practice and one that is likely to give the child feelings of insecurity and confusion. If the child's family needs more support than is available from one residential care facility, then additional ways of help should be considered to supplement the support

being given by the one facility, such as home help, a sitting-in service or day care.

21 The practice of giving young handicapped children recurrent experiences of short-term residential care as 'a preparation for adult life and independence' should be condemned on the grounds that such an experience is not commonly advised as appropriate for young children who are not handicapped and it is not commensurate with normal principles of child care.

22 Any forms that the parents are asked to fill in about their children should not only contain questions about their disabilities and weaknesses but also about their abilities and strengths.

23 One member of the care staff should be responsible for ensuring that parents' information about their children, contained in the forms they have filled in, reaches all members of care staff and is understood by them and acted upon as necessary.

24 Each child's short-term care arrangements should be reviewed at regular intervals (not longer than six monthly) to ascertain whether they are still needed and desirable and are not causing the child any problems.

25 School transport should not be used for getting children to the short-term care facility unless the professionals and parents are quite certain that the children are not upset by the arrangement.

26 Children should not start having short-term residential care during their first year at school. Having to adjust to residential care at the same time as adjusting to school will make too many demands on them.

27 Parents and professionals in contact with the children, for example, teachers and care staff, should communicate with each other regarding the children's reactions to the experience of being separated from their families.

28 Teachers may help to reassure the children about short-term care by encouraging them to talk about it at school, treating it as a positive and happy experience, and referring to it in school 'newstime' and projects.

29 A member of the teaching staff of local special schools whose

pupils are having short-term care might be designated as the link person between school and the short-term care facility, to communicate any information about the children and their needs, what they do at school, and any problems that may arise in school because of the short-term care.

30 All short-term residential care units should have a clearly defined written policy regarding homesickness. The policy should refer to its signs, its causes, ways of helping to ease its pain, whether it can be prevented, how it may show itself in children of varying ages. All members of the care staff should read and be familiar with this written policy on homesickness.

31 Care staff should be alert to signs of homesickness amongst the individual children for whom they are caring.

32 Professionals of all disciplines and at all levels should beware of assuming that children who have very profound multiple handicaps do not have the same feelings as other more able children, and they should discount any suggestion that these children do not really know where they are.

33 The care staff should be organised for individual child/staff assignment as this encourages individual attention and mothering care.

34 It should be remembered that one of the most basic principles in caring for children away from home is that they should retain and use their personal belongings, for example, toys, clothes, toiletries.

35 Children away from home need to be given reassurance and a feeling of security; personal routines such as bed-time, bath-time, toileting and mealtimes are an opportunity for staff to give individual caring and mothering. Whenever possible the children should always have the same member of staff attending to them. When this is difficult to arrange, every attempt should be made for them to have as few changes of staff as possible.

36 In any residential setting there is a risk that some children will receive little or no personal attention except that which is needed to attend to their essential functional needs (cleanliness, clothing and food). Staff should be aware of this fact and try to ensure that each child's mothering needs are being met and, if it is difficult to

meet their mothering needs, the staff should consider what is causing the problem, for example, is it due to shortages of staff or lack of understanding of children's needs?

37 Written records about the children's behaviour during their stay should not be merely a record of their eating and sleeping habits and bowel movements and medication, but describe their daily activities, their play, their response to adults and other children, their apparent reactions to being away from home and their conversations and questions.

38 One way of helping children to understand about short-term care and develop positive links between the facility and their family might be for them to keep a scrap book with photographs of staff and parents and the residential facility and their own home, and pictures of where they have been and what they have done in both places. The staff and their parents can talk to them about the pictures as they look at the book.

39 The children should always be given clear and honest explanations about going away into short-term residential care. Lies and secrecy should be avoided. The staff should be aware of any difficulties that the parents might have in telling their children about going into short-term care, and they should discuss with them how the children might be helped to understand about it.

40 News notebooks about the children should be sent to and from the facility and the children's homes with the staff and parents using them for sharing up-to-date information about the children and their recent activities, progress and interests. These notebooks would not be a substitute for personal contact between staff and families, but a helpful addition to developing positive contact, and they would be especially helpful if the children are very handicapped and unable to communicate.

41 Any interests and activities regularly enjoyed by the handicapped children when they are at home should be continued when they are receiving short-term care, for example, attendance at clubs, Guides, swimming lessons, horse-riding.

42 Parents starting to use short-term care for their children should be given explanations about the normal effects of separation experiences on children, and have opportunities to discuss the likelihood of their own child being homesick and/or showing some

later adverse reactions to the experience of being away from home.

43 Staff meetings should allow for critical discussion about the quality of child care and relationships between staff and children; they should consider such problems as why it may seem easier to relate more to some children than others, consider what may be particularly good or bad in the care they now give, and list ways that child care may be improved.

Concerning parent management

44 Residential care staff, field workers and managers of short-term care services should have discussions with local parents and try to define the degree of involvement that they might have in sharing the management of local short-term care facilities, and consider the extent to which parent involvement in management means a voice in the day-to-day organisation of child care.

45 Even if a service seems good, there is a need for parents to be vigilant in monitoring its quality and developments. There is a danger of parents being so pleased with a local service starting up that they become over-confident about it and fail to notice changes in the quality of the care their children are receiving.

46 Parents and professionals should have regular meetings together to look critically at the local short-term residential care services and list ways of improving them and discuss exactly how these improvements might be achieved.

47 Parent/staff associations should not concentrate only on fund-raising but remember that they have an important role in helping parents and staff to jointly consider the quality of child care in the facility and the degree of support that the care staff should receive from their senior managers in order to successfully fulfill their task of caring.

48 All parents should have opportunities to give individual critical opinions about short-term care services, especially any dislikes they may have about the practical care of their children and/or the emotional impact that the separation experience has on the child and the rest of the family.

49 Meetings between staff and parents should permit a free exchange of views and ideas, and staff should beware of reacting to

criticisms in a defensive manner which will prevent them from recognising deficiencies and planning improvements.

50 Notes which the residential care staff have written about the children during their stay should be available to the parents if they wish to read them.

51 Any special programme that the child is on (for example, practising or learning skills or controlling behaviour), should be fully discussed by the parents and care staff and other involved professionals (teachers, psychologists, physiotherapists and speech therapists) and a joint decision should be taken on whether or not to suspend the programme whilst the child is having short-term care.

52 Residential care staff should never put a child on to any sort of training programme without first discussing it with the parents and obtaining their agreement.

53 Decisions about the child's care, such as hair-cutting, changes in medication, seeing a doctor, should never be taken without first consulting the parents and getting their agreement.

54 Within one week of a child's return home from his or her first experience of residential short-term care the parents should be visited by a social worker or community nurse or one of the residential care staff, and their opinions should be asked about the service and any worries that may have occurred because of it.

55 The larger residential care facilities might consider making one room available for parents to use as their own as a place to make coffee in and have a rest when out shopping, where they can meet each other for a chat and where they can keep all relevant literature and up-to-date information leaflets.

Concerning the quality of contact between care staff and parents

56 It should not be assumed that parents will know the care staff simply because their children are regularly using the facility. The possibility of contact between staff and some parents being almost negligible should be discussed at staff meetings.

57 Staff meetings should permit critical discussion about the quality of contact between staff and parents, consider why it seems easier to make contact with some parents rather than others, consider

what may be good or bad in present contacts, and give opportunities for staff to plan ways of improving their contact with parents.

58 The importance of staff and parents knowing each other should be explained to new staff and emphasised at inservice training sessions.

59 All the care staff should be aware of the need for good practices in making contact with families: these cover greetings, introductions, sitting down and talking to parents, letting them know that their child is known and liked, letting them know that he has been carefully looked after, farewells.

60 Care staff should make certain that all parents are made obviously welcome whenever they come to the facility, through welcoming social behaviour such as friendly greetings, introductions by name, making eye-contact, smiling, speaking to their child if he/she is with them, finding some time for conversation as opposed to mere greetings in passing.

61 The care staff should always introduce themselves by name to the less well-known or newer parents when they meet them in the facility or speak to them on the telephone.

62 Care staff should make certain that they always answer the telephone in a friendly manner.

63 If the facility has child/staff assignment the parents should always be told and introduced to the special member of staff who has been assigned to their child, and they should be able to telephone or see him or her if they wish.

64 Care staff should be able to visit the children's homes and talk with the parents about the care of their children if the parents think this would be helpful.

65 Booking-in procedures should be regularly and critically examined by parents, care staff and senior managers of residential care services to see if the procedure currently used encourages or discourages good contact between care staff and parents.

66 The use of school transport to get children to and from the residential unit should be avoided, not only because it may upset

the children (see guideline 25) but because it also prevents contact between staff and parents. Other means of getting children to and from units should be decided, for example, voluntary drivers with the parents as escorts, or the facility's own transport going to the children's homes and fetching and returning them.

Concerning siblings and grandparents

67 It should not be assumed that all siblings always feel pleased about the handicapped child having short-term care.

68 Parents should be given opportunities to discuss with the care staff and other relevent professionals the reactions and opinions of the siblings regarding the handicapped child's use of short-term care.

69 The siblings should visit the residential care facility and see where the handicapped child will be staying, and they should be introduced to staff and made generally welcome.

70 Care staff and other relevant professionals should be aware of what contact the families have with grandparents.

71 Whenever possible the involvement of the grandparents in the family should be considered when decisions on short-term residential care are taken.

72 Professionals should be alert to the fact that grandparents may feel upset about the use of short-term care and this may create additional stress on the family. Care staff might consider helping with this problem by making the grandparents welcome in the facility and ensuring that parents have a leaflet about it to hand on to grandparents who live too far away to make a visit.

Concerning the professional development of the care staff

73 All residential care staff should have regular inservice training, attending, if possible, an annual three-day general training course away from the facility in which they work. The course should cover the following topics: child development, child care, children's reactions to loss and separation, the special needs of handicapped children, the needs of families, the latest national developments in mental handicap services, and local government management of health and social services.

74 In addition to the inservice training suggested in guideline 73, there should be occasional training sessions within the facility to encourage all levels of staff to look critically at their own work; which covers: parent contact; meeting the needs of individual children in a constantly changing group of children and staff; the importance of play; supporting each other; guiding new members of staff (especially those who are school-leavers in their first caring jobs); links between the facility and the neighbourhood; whether the aims and organisation of the facility need changing and how such changes could be accomplished.

75 It may be helpful for three or four short-term residential care facilities in different districts to form continuous links with each other for the purpose of visiting each other's premises, comparing and discussing their development and mutual problems, having inservice training days together. This professional link system could ease the professional isolation felt by some residential care staff who may have had few opportunities for further training or visiting other districts to meet staff working in similar facilities.

Hopefully, the 75 guidelines listed in this chapter, considered in conjunction with the contents of the previous chapters, will be helpful in planning or improving children's short-term residential care services. An area of need which has not been referred to in this research is the problem of the school holiday placement of handicapped children who are attending boarding schools run by local education authorities or voluntary organisations and who are without families or have little or no contact with their families. In the early stages of planning this research project it was hoped that these short-term care school holiday placements would be investigated, but the immense problems of these children (some of whom have two or three difficult residential short-term care placements every school holiday), turned out to be beyond the scope of this piece of research. It is hoped that future research will one day investigate the needs of these children and draw up guidelines regarding their care, because giving them a multiplicity of residential placements during boarding school holidays should be fully recognised as a poor practice.

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8 Aspects of special short-term fostering care

The development of special short-term fostering care

In the latter half of the 1970s, special short-term fostering schemes were set up by a small number of local authorities as a recognised form of community support for parents of mentally handicapped children. These schemes were separate from the legislation of the Children's Acts which were a necessary part of ordinary fostering; they were provided under Section 12 of the Health Services and Public Health Act 1968 (Section 21 and Schedule 8 of the National Health Services Act 1977). Under this legislation the handicapped children did not have to be taken into the care of their local authorities as they would if fostered under the Children's Acts; thus, their parents did not lose their rights over them.

Before the mid-1970s and the official development of the special schemes it was not unknown, of course, for some mentally handicapped children to be given occasional short stays with a foster family without being taken into the care of the local authority under the legislation of the Children's Acts. These were usually cases where a social worker knew that a family needed a rest and there was a foster parent who would not mind looking after a handicapped child for a few days. In retrospect it is obvious that these short periods of 'unofficial fostering' were the first tentative attempts to provide parents with neighbourhood support by letting their children stay with other families as an alternative to sending them to hostels or hospitals for short-term care. However, such help was rare and there are no national figures regarding the frequency and location of these arrangements. Curiously, even after the special short-term fostering schemes began to rapidly develop in different areas across the United Kingdom, from the late 1970s onwards, there were still some local authorities who did not set up their own special schemes but continued to provide 'unofficial fostering' with ordinary foster parents for a small number of young handicapped children.

The first special short-term fostering schemes for mentally handicapped children to be set up under the Health Services Acts were initiated in 1975 by Paula Toyne of Somerset Social Services Department, and by Malcolm May, Ian Crosby and Derek Naylor of Leeds

Social Services Department. These senior workers have to take every credit for innovating a completely new form of community support for mentally handicapped children, instead of following the tradition of providing care in segregated institutions. The ideas of Somerset and Leeds have resulted in a nationwide development of short-term fostering schemes for handicapped children; by 1983 there were more than 50 local authorities providing them.*

Some of the parents who are now happily using short-term fostering were not very keen about the idea at first (see also page 87 and Table 5). Their initial trepidation was mainly because the thought of letting their children be looked after by other families seemed to suggest that they themselves were failing as parents. Unfortunately, because the word 'fostering' has connotations of parents being in need or in trouble or even feckless and neglectful, some parents of handicapped children have continued to resist the idea of using special short-term fostering. They feel it is more acceptable to send their children to mental handicap hospitals for short-term care (no matter how unsuitable these places might be) because going to stay in a hospital suggests that they require medical and nursing care, whereas going to stay with another family seems to cast doubts on the parents' ability to look after them.

In order to distinguish the schemes from ordinary fostering and convince parents that short-term fostering is not a criticism of their own care but a new and satisfactory means of getting regular help with their handicapped children, the organisers usually give special titles to the schemes – for example, 'Befriending Service', 'Substitute Family Care', 'Caring Family Scheme', 'Partners', 'Link Families', 'Help a Child Scheme', 'Care for a Child Scheme', 'Home from Home'. It is a pity, however, that the honourable task of caring for other people's children through fostering is apparently held in such low esteem that it has been necessary to think up new titles for the mentally handicapped children's schemes. In the best sense of the word, to foster means to cherish, nurture, watch over, safeguard, cuddle, treasure, care for and love, so it seems to be a very satisfactory word to use when describing the care of children away from home. Therefore the terms *special fostering* and *special foster parents* have been used throughout this chapter instead of one of the many titles used by local authorities.**

Although it seems regrettable that such pains have been taken to distinguish the special fostering schemes from ordinary fostering, there are, of course, some very obvious differences. For example, an

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*By 1990 there were 220 schemes in the UK. (Figure from Christopher Orlik in a report to the National Association of Family-based Respite Care, 1990.)

**By the end of the 1980s, the word 'fostering' was rarely used; the term 'family-based respite care' has been nationally recognised as the most appropriate.

integral part of the special schemes is that the majority of the natural parents and the special foster parents build up friendly relationships with each other through careful introductions and preliminary meetings; this is unlike the majority of ordinary fostering arrangements, when the two sets of parents may never meet or be encouraged to make a helpful relationship.

A second difference is that the people applying to work as special foster parents include a large proportion of middle-class people who would not have thought of fostering ordinary children but, from a mixture of interest and altruism, are attracted to the idea of helping handicapped children. For example, in one district there was a group of 20 special foster parents giving a regular service to parents of mentally handicapped children. But only four had been ordinary registered foster parents; the other 16 had a variety of professional backgrounds and experience.

A third difference is that special foster parents are paid more than ordinary foster parents. Payment was approximately £66.00 a week in 1983. This chapter does not consider payments of special foster parents or the financial advantages of these schemes as opposed to care in hospitals or hostels, but it is obviously cheaper to recruit and pay special foster parents than to build and maintain a new hostel or upgrade a hospital ward for the purpose of providing short-term care.* A hostel will not only demand a capital outlay of approximately £300 000** but will consume thereafter an annual revenue cost regardless of whether or not the beds are kept filled all the year round; in 1983 the cost of keeping one child in a 20-bedded hostel was £250** a week. This figure covered staffing, maintenance of buildings and gardens, rates, electricity, catering and insurance. In contrast, all the financial outlay for special foster parents goes into giving *direct care* to *individual children at the time they are receiving it.*

This chapter makes no claim to be a comprehensive assessment of special short-term fostering care. It merely discusses the experiences of a small number of special foster parents and considers some of the advantages and pitfalls of the schemes. The following stories are based on real situations but the names have been changed and some of the circumstances have been altered or amalgamated in order to maintain confidentiality and respect for the many families who willingly gave information for the study. (I am especially indebted to families and professionals in London, Somerset, Yorkshire and Northumberland for the information and ideas incorporated in this chapter.)

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* Readers wishing to have up-to-date information about financing short-term fostering schemes should write to some of the many local authorities which are now providing the service; they might then like to compare the figures with the capital and revenue costs of a hostel or hospital.

** Approximate 1983 costings.

Six special foster families

> *'These schemes are tailor-made for parents who want their children to receive individual care in a proper family home.'* (*Mother of a handicapped child.*)

Mr and Mrs Erikson were in their mid-40s, with two adolescent children still living at home and a son in his 20s at medical school. Mr Erikson was a teacher in a local school for physically handicapped children. Mrs Erikson had been a florist before her marriage. They learnt about the special fostering scheme from an article in a local newspaper. Mrs Erikson was interested in voluntary work and her husband's special school, but had never worked with handicapped children. She had been thinking of getting a job with children now that her own were growing up, and it seemed an incredible stroke of luck to suddenly find a job with children which she could do at home. She and her husband discussed the idea with their children before they applied to be special foster parents, and Mrs Erikson explained to them that she wanted some work and an interest of her own now that the family was growing up. Their 15 year old son said it would be fun to have the children coming to stay, but their 18 year old daughter, in her final year at school, was not keen at first. Later on however, after leaving school, she became very interested in the children and started to help at the handicapped children's club one evening a week.

Having the children to stay did not demand a great change in the Erikson's life-style. They still went out in the car at weekends and had their friends in. The biggest change was having to put away their ornaments and more expensive items of furniture when certain children came, to prevent damage or breakages which would be upsetting and cause embarrassment between them and the children's parents.

Mrs Erikson said that since starting the work she seemed to be also a public relations officer for handicapped children. For example, because of the scheme her neighbours had been introduced to handicapped children for the first time and had found that many of their misconceptions and prejudices were unfounded; one neighbour was now applying to be a special foster parent herself.

Mrs Erikson took children aged from seven to 15 and they had a wide range of handicaps; some had behaviour disorders, others were cerebral palsied or had multiple disabilities such as blindness or deafness in addition to severe mental handicap. Her biggest dread before starting had been if a child had a major fit or became ill, but these fears had been needless. She had coped with the occasional fit, and none of the children had been ill. The biggest problem had been learning how to cope with seven year old Frank who was mentally handicapped and profoundly deaf. He would get very frustrated and upset when people did not understand his attempts to communicate. At first the Eriksons had been 'almost frightened' when they had not understood what he was trying to tell them through his signs. However, after he had stayed with them three times Mrs Erikson began to feel more confident about signing with him and she was now 'very attached' to him. Now, if the Eriksons went out for a drive at weekends when he was not staying with them, they would often call on his family and take him out for a few hours.

Frank's school teachers and his parents helped Mrs Erikson to cope by teaching her his sign language. But learning to cope had also been related to the building up of a secure relationship between her and Frank. During the summer, when he had stayed with them for one week every six weeks, he used to get up very early and Mrs Erikson would take him into the garden and they would pick flowers and arrange them and then do some baking before anybody else got up. 'It was in those early summer mornings together that we first clicked, and then there was no looking back' she said.

She had always found the children's teachers very helpful. They were willing to talk about what the children were doing at school and how to communicate with those who could not speak or hear. But she thought that contact with the children's parents was the most important of all. A trusting relationship with parents was crucial and it was better not to take a child if the parents were not happy about the placement. The good relationship had to be worked at, it did not occur automatically through one introductory meeting. In early meetings with parents, there was often a sense of shyness and awkwardness as both families wondered about each other. Mrs Erikson had spent many hours building up her links with the children's parents, and believed that working on the scheme was not just having the children to stay but being involved with the whole family if necessary. She had found it helpful to visit some of the parents in their own homes several times before they developed enough confidence to let their children come and stay with her.

She described Mr and Mrs Murphy, the parents of Bill, as very cautious and suspicious in the beginning. They were puzzled about why anybody should want to look after a handicapped child and they queried the Erikson's motives for being special foster parents. And the fact that the Eriksons were obviously comfortably off financially seemed to make Mrs Murphy very suspicious. They made almost impossible demands at first, and had been quite rude on occasions, but Mrs Erikson's patient response had gradually won their confidence and helped them to voice their anxieties and finally accept the fostering help. Both families eventually became personal friends.

Bill Murphy had never stayed with anyone before he went to the Eriksons, not even his aunts and grandparents would have him because he was so difficult. His parents said that their friendship with the Eriksons and the support they got from them in sharing Bill's care, had made 'an incredible difference' to their lives; they could not accept any help with his care until they were absolutely sure that he himself liked the people he was going to stay with, and that they understood his difficulties. During Bill's third stay with the Eriksons his parents spent a week in Wales. It was their first holiday for seven years.

Mrs Murphy said, 'We were impossible at first. We all laugh about it now. I went round there and wanted to see all over their house, and I wanted to know if he could take his own pillow, a special jigsaw, dominoes and books and his electric blanket. And I kept on that Mrs Erikson would have to follow all his routines. I could never have made those demands on care staff in a hostel or on hospital nurses, of course, because I would have been conscious all the time that there were other children beside Bill to consider. These schemes are tailor made for parents who want their children to receive individual care in a proper family home'.

One of Bill's familiar routines which the Eriksons were happy to follow for him was his 'electric blanket game': before he got into bed at home his mother always made a game about turning off the electric blanket and taking it out and then he would leap into the bed and snuggle down very quickly between the warm sheets and bring them right up to his chin. This bedtime mothering game was important to Bill and his mother, and the fact that Mrs Erikson followed it when he was staying with her made his parents feel happier about the separation.

In trying to sum up what the scheme had done for them, Mr and Mrs Murphy said:

'The responsibility is shared.'

'In a crisis we know there is somewhere for him to go.'

'If I had something wrong with me I would go and have a check-up now, knowing that there would be somebody for Bill to go to if I was ill. Before, I was not able to face up to the idea of being ill because of the fear of what would happen to him if I could not look after him.'

The Erikson's advice for anybody deciding to be special foster parents was: 'Learn as much as possible from the children's parents and teachers and then carry on the same routines as they have at home'; and 'Let the children see that you are friends with their parents so that they do not think they are coming to stay with complete strangers'.

They thought that one of the beauties of the scheme was that there was no hierarchical structure to it, no career or promotion prospects; all the special foster parents were equal and were only interested in the children and in giving a service to the families. They said that they got immense satisfaction from being special foster parents, but after having worked for three years on the scheme Mrs Erikson was conscious that she was rather over-committed to it and it worried her to think that if her husband changed his job and they had to move out of the area they would let down the families they were regularly supporting. This was a very common worry amongst the special foster parents. Mrs Erikson hoped that in building up a relationship with the families she had also giving them enough confidence to help them transfer to other special foster parents if necessary without feeling it was too much of a disaster. But she wondered if they would really be able to do so, as such personal relationships might not be easily transferred to other people.

'I have got two lovely Mums, one at home and one here.' (Short-term foster child.)

Mr and Mrs Roche were in their early 30s. Mr Roche was a hospital laboratory technician and Mrs Roche had been a nursery school teacher before her marriage. They heard about the special fostering scheme on the local radio and were attracted to the idea of helping parents of handicapped children and keeping the children out of the local mental handicap hospital; the radio programme had stressed this latter point as one of the main advantages of the scheme. They began the special fostering work when their own three children were aged eight, six and one. Their only previous experience of meeting handicapped children was through Mr Roche doing voluntary work at a club for physically disabled people.

Their training for the special fostering consisted of visits to some special schools and a hospital 'to see handicapped children'. They thought these visits were interesting but not particularly helpful because they highlighted the children's handicaps and almost put them off. What worried them most before they started was whether their own children might be frightened if a handicapped child had a fit, but this fear had been groundless because the children with epilepsy had regular medication which kept their fits well under control.

Their worst problem had been caused by a mother not telling them that her child was a persistent crier in case they refused to take him. The Roches had been very upset when they could not stop his tears and thought it was because he was homesick. They were unable to contact his mother because she had gone out for the day and they spent a very anxious six hours before they finally reached her. She then told them that persistent crying was her son's main problem and the reason for her needing a break. Mrs Roche said that after this she stressed the need for complete honesty between the parents and special foster parents. Without honesty they could not help each other.

Changes in the Roche family life-style were inevitable during the weeks that the children were visiting. They were slightly more restricted and sometimes unable to do all the things they wanted to with their own children. For example, one handicapped child's visit had recently coincided with their own children's school concert and only Mr Roche was able to go. Mrs Roche stayed behind with the handicapped child who was then staying with them because he was too overactive and noisy to take. They also changed their shopping routines, doing a big shop the week before in case it was difficult to get out. And they occasionally altered their eating habits so that the handicapped children would feel more at home; for example, having more traditional meat dishes instead of their usual salads and health food meals.

Mrs Roche said that two aspects of the scheme gave her particular satisfaction. One was when the handicapped children showed affection and she described one of them looking around at the table at lunchtime one day and saying 'I have got two lovely Mums, one at home and one here'. The other was when she noticed her own children gradually developing love and friendship for the visiting children and looking forward to them coming back again. Their eldest daughter had become so fond of two particular children that she sometimes cried when they went home again; and she had recently joined an integrated children's club and was helping at a mentally handicapped children's playgroup in the school holidays. One of the many advantages of the schemes is that they are a good means of promoting integration between ordinary and handicapped children.

If any very difficult children were coming to stay, Mr and Mrs Roche explained to their own children that it would be wise to put away their more fragile toys in case they got broken. Their middle daughter had once had her toys broken because she left them out when a very active boy came; they had then thought momentarily of withdrawing from the scheme because she was upset, but decided that the friendships which had developed between their own children and the handicapped children far outweighed the problems that occasionally occurred.

The Roches, like the Eriksons, felt that through working on the scheme they were helping their neighbours to meet mentally handicapped children and overcome some of their prejudices about them. However, they had difficulties with their own parents, who disapproved of them doing the work because they thought they would get overtired and then not look after their own children properly. And Mr Roche's father got upset when he saw very handicapped children and said that they 'should not be allowed to live'.

The Roches were always careful to keep to the visiting children's familiar routines, and thought it was especially important to let them have their comfort toys at bedtime as that was a time when they might begin to wonder where their parents were. Mrs Roche said that some of the children showed signs of homesickness, being a 'bit weepy' and 'looking around and asking where mum was', and the more handicapped children who could not speak or walk sometimes 'stiffened up and seemed uneasy' for a few hours after they arrived and she had to cuddle them and get their confidence. She did not think homesickness was a major problem but thought that all special foster parents and the children's parents should be aware of it. Meeting the children with their parents and letting them see and know that they were all friends together was one way of easing any strangeness.

The Roches preferred to have younger children because they fitted in well with their own children's interests and needs. One afternoon I visited them when they had two handicapped brothers staying with them for a week. Whilst I was there the boys arrived back from their special school and ran indoors through the kitchen just as two of Mrs Roche's own children were also arriving home from school. 'Put your slippers on then' she called out, and all four children got their slippers from under the cooker and came into the sitting room and fetched some toys over to sit on the mat with us in front of the fire. They sat there playing together, sharing the tea and cakes that we had left, and the contentment and integration of the two handicapped children into the ordinary family environment, as if they were visiting an aunty and uncle and cousins, was in striking contrast to the quality of short-term care given in hospitals and hostels and described in Chapter 6.

The Roches had helped eight families in two years. Three families were on a regular basis, and five had received occasional holiday care in August and at Easter. Over the last year they had started to give intensive help to one particular mother. She was widowed and had three very active, mobile and mentally handicapped sons and was herself incapacitated by a deteriorating physical illness which had confined her to a wheelchair. This sick widowed mother would have had to let her children go into a mental handicap hospital for long-term care if she had not received regular help from the Roches. In supporting her they were not only helping to keep the family together and enabling the children to remain in the community, they were also saving the statutory authorities some considerable expenditure. For example, the regular help given by the Roche family one week each month to these three children was costing the local authority social services department £2340 a year (1982) for actual time given in direct care, but if the *three* children had been placed in a Home or hospital for permanent care, it would have cost the local authority an annual sum of £39 000 in a 20-bedded hostel, and the health authority an annual sum of £25 500 in an NHS mental handicap hospital.*

Mr and Mrs Roche's advice to new special foster parents was: 'Always think of the children as being normal, as normal children with special needs and not as handicapped children'.

'Do not look for pats on the back and get the idea that helping handicapped children is something rather wonderful—only do it because you like children'.

Their biggest criticism of the scheme was that it was only for children up to the age of 16. They thought this rule was going to break off some very important relationships as the children reached the age of 16 and had to stop coming.

Summing up how she felt after working for over two years as a special foster parent, Mrs Roche said she now wanted to concentrate on helping two small girls who had Down's syndrome, and the three children of the disabled mother. She had decided that she would not take anymore very helpless cerebral palsied children because she could not reconcile herself to their deformities; those she had taken had only been on occasional holiday visits in August so she was not letting down a regular contact by no longer having them.

Mrs Roche felt very distressed about taking the more severely multiply handicapped children, but this had not been sufficiently recognised by the social workers who had arranged their placement. One particular child had come with his mother and the social worker on two introductory visits, and although Mrs Roche knew that he was very helpless, she had not realised exactly how terribly deformed he was until she was on her own with him and undressing him for the first evening with her, and then she saw his little twisted legs and body.

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*Approximate figure for 1983. The hospital figure is the costing for a mental handicap hospital in the South West Thames Region for 1982–83.

'When I had seen him sitting on his mummy's lap in his clothes, I suppose I knew he was very handicapped, but perhaps didn't take it in how badly; it was when I undressed him and saw his poor little legs—I wept for him.' She wished that she had been able to talk with his mother and the social worker about his dreadful handicaps before she had seen him undressed. Later on she did talk to his mother and she then felt a little less distressed, but her first sadness at seeing his multiple handicaps remained with her and she continued to feel that cerebral palsied children were just too heartbreaking for her to cope with.

'She is the finest friend that we have ever had.' (Father of a handicapped child.)

Mrs West was a 62 year old widow. She heard about the special fostering scheme on the local radio and thought it was voluntary work. When she contacted the Town Hall to offer her help she was astonished to learn that it was paid work which required an interview and training.

About 15 years earlier she had worked for a short time as a nursing assistant in a mental handicap hospital so she was not worried about the children having fits or being very handicapped. Her biggest worry was whether they would be very homesick and how she would cope if they missed their parents and kept crying and wanting to go home. Although homesickness had not turned out to be a major problem she still felt bothered about it when having new children in case they did not 'take' to her.

Mrs West had two adult sons, both married and living away from the district, but no grandchildren. One of her sons had misgivings about the wisdom of her taking on the care of handicapped children single-handed when she was over sixty, but he now appreciated that she was getting happiness from doing the work.

What she especially liked about the scheme was having children about the house again. 'It is like being a mother again.' Her aim in doing the work was to give grandmotherly care to the children and make sure that they were happy with her and enjoyed their stay. She would not take any teenage boys or over active children because she did not feel that she would be able to cope with them on her own. The tips she said she would give to people just beginning to start special fostering were:

'Visit the special schools and get to know the children's teachers'; 'Make sure that the parents have been to your home several times first, so that they know where their children are coming and what you are like yourself'; and 'Be patient with the children'.

She said the only disadvantage of the scheme was that she could not go out as much as usual when the children were staying. She tended to stock up with shopping the week before and if she needed anything extra she used the little corner shop instead of shopping in the city for it. She did not feel that she could manage the handicapped children on a long bus journey into the city.

She had helped seven families on a regular basis for just over two years. One of her special gifts was the grandmotherly affection that she gave to the families she was helping. For example, the Scott family had been having regular help from her from two years in caring for their six year old daughter Dina—she was lively and slightly physically disabled as well as being mentally handicapped. She started staying with Mrs West just before her fifth birthday. When her parents were first offered special fostering help they had felt very dubious, their first thought being 'Who on earth would be able to manage Dina except ourselves?' However, they decided to try the scheme because Mrs Scott had a chronic physical illness and there were three other young children in the family.

Mr Scott said that the first time he took Dina to stay with Mrs West, after they had had three successful introductory visits, he drove very slowly along the road thinking to himself, 'If you cry, just once, I'll take you straight home'. On that first occasion she had cried for a time after her father left and she had obviously wondered about his absence. But on subsequent stays she waved goodbye happily to him and then went to get the little box of pots and pans that Mrs West kept for her and climbed up to the sink to play with the water.

One of the advantages that Dina's parents had found about her visits to Mrs West was that some of the skills which they had been struggling to teach her at home, but could not consistently help her with because of the mother's recurrent illness and the needs of the other young children, seemed to fall into place when she stayed with Mrs West. For example, how to drink from a cup and how to use the lavatory. They thought that this was because Mrs West had the time to give her the individual attention that she needed in practising the skills. Her parents were not upset or jealous when Mrs West was successful in teaching Dina anything, they were just glad that the groundwork that they had put in when trying to teach her these skills at home had flowered when she received a lot of individual attention from Mrs West. 'She always seems improved when she comes back, somehow calmer and more sensible' said the father.

Dina's sisters had been rather jealous at first about her 'holiday with Auntie Flo' but they gradually accepted their parents' explanations that Dina needed extra help and was sometimes tiring for their sick mother. The sisters told their friends that she was 'staying with aunty' and sometimes they would go with their father to fetch her home again and then have tea with Mrs West.

Mrs West and the Scott family were an example of all that is positive in the special fostering schemes. Although Dina's parents had so badly needed help in caring for her they would never have used a hostel or hospital for short-term care. The help given by Mrs West was the only form of support acceptable to them. Some of the success in their relationships was probably due to Mr and Mrs Scott not having any parents of their own, and Mrs West not having any grandchildren. The scheme had filled a mutual gap for the parents and Mrs West—she had become the substitute grandmother they needed and thereby found the grandmother role that she wanted. 'Working on the scheme makes me feel ten years younger. I'm a new woman. If a family says that I've helped them that is nice of course, but they helped me just as much' she said. 'She's the finest friend that we have ever had', said Mr Scott.

'I could not believe that anybody else would change my son's nappies for me. She is just an ordinary mum too, like me, living in an ordinary house . . .' (Mother of a handicapped child.)

Mr and Mrs Brown were in their early 30s, with two boys aged ten and twelve. Mr Brown was a social worker and Mrs Brown had been a dental receptionist before her marriage. Their previous experience of handicapped people had been through Mr Brown's professional interest in families with handicapped children. They applied to be special foster parents because they wanted to help families.

Before they started they were concerned about how they would communicate with very handicapped children who could not speak, how they would safeguard children who might be inclined to run out of the house onto the very busy road, and how they would cope with children who had multiple physical handicaps and needed to be fed; but these worries diminished after they had began taking the children. The main problem turned out to be lack of sleep, which was something they had not anticipated. Loss of sleep was not necessarily because the children had disturbed nights but because the Browns were very conscious of them being in the house and felt that they should not sleep too deeply in case they were needed in the night. With regard to their worries about the very helpless children, they had been nervous in the beginning about picking them up and bathing and dressing them because they thought they might hurt them, but with advice from parents, they gradually gained confidence and realised that the cerebral palsied children were not always as frail as they appeared at first sight.

They thought that differences in family background and unbringing were not sufficiently acknowledged by the organisers of the scheme and sometimes presented problems which, in a subtle way, were more difficult than the children's handicaps. For example, one small child had a habit of spitting and swearing at them; 'We took ages to accept him but are OK now'. They found that barriers that might have been initially caused by differences in family background and culture were always broken down once they got to know the children, and they felt that one of the most satisfying aspects of the scheme was the awareness of friendship growing between themselves and the other families.

The Browns thought it was absolutely essential to listen to the parents and follow out their particular routines. They recalled the parents of one child saying he always had to go to sleep on the settee first and then be carried upstairs and put to bed, but they thought they could put him straight to bed and thereby make him change his sleeping habits. This idea had been a failure because an hour later they went upstairs expecting to find that he had gone to sleep as they planned but found that he was still awake and had smeared his faeces around the room. After this they followed his parents' instructions.

That child's habits might have been altered by putting him on a training programme with the cooperation of his parents, his teachers, the special foster parents and a psychologist, but until this happened the Browns found it was best to follow his parents' routines, no matter how unconventional. They did not think that it was up to them to initiate changes in parents' long-established routines. In fact, they thought that the beauty of the fostering scheme lay in its simplicity. It was built on a philosophy of developing a good relationship between fostering families and natural families and it would have been a pity to spoil it by introducing more sophistication, such as the special foster parents going on courses to learn behaviour modification techniques or physiotherapy. They agreed that they needed to understand the children's handicaps but did not think that they should set themselves up to be anything more than substitute parents offering family style care based on the same routines as the children were used to at home.

One of their most successful contacts had been helping the parents of 11 year old Paul, the only child of Mr and Mrs Carter. His parents had not expected him to be accepted on the scheme because he was so difficult. He had habits of biting and pinching and he would not tolerate any furtniture such as ornaments, standard lamps, flower vases and pots. His over-active spiteful behaviour had worsened since he had started at special school and grown bigger. He was no longer accepted by the other children in his road and, because of his increasingly difficult behaviour, his parents' social life had petered out. They tended to isolate themselves in the house during the evenings and at weekends, their only outside life being an occasional car trip into the countryside. Paul's father worked away a great deal and Mrs Carter had been very isolated in the evenings and at weekends until the Browns started to share Paul's care.

Mrs Carter said that apart from the physical rest that the scheme gave her, the best thing about it was Paul being accepted into a normal family environment and getting to know children who were not handicapped. At his special school he was in a class for the most difficult children so he only saw very severely handicapped children who were like him, over-active, speechless and destructive. The segregated life he led, seeing only other severely handicapped children all day at school and then just his parents in the evenings and weekends, had not helped him to be more normal. Now, his integration into the ordinary family life of the Brown's home and his friendship with their two sons was giving him a positive experience of a completely different way of life.

His mother said that he obviously liked it with the Browns; he remembered the route there and was excited and happy as his parents drove him there. And when he came home he always seemed calmer and better behaved. She thought, however, that he sometimes showed a slightly resentful reaction towards her when he came home; he would turn his head away from her and be 'a bit remote' for the rest of the day. She felt that this was his way of telling her that he had missed her, and she did not worry about it unduly because she thought that the advantages of his staying with the Brown family were so immense.

When the Browns had Paul to stay they locked their lamps and vases and ornaments in their spare room, and kept their living room and dining room very bare, like his own home. They found him very tiring because he needed constant watching, but knowing that they were helping his parents and giving him the experience of coming to stay with them in a normal environment instead of going to a hospital was very satisfying.

The scheme had boosted the Carter's morale enormously. Having their very difficult child accepted into another family they felt, for the first time since he had started going to special school, that they were no longer an isolated and handicapped family (see also page 103). One of the major advantages of using other families for short-term care instead of hostels or hospitals is that parents get this much needed boost to their morale; having their handicapped children accepted by other families is proof of their acceptance by society, and the parents' previous feelings of social rejection are reduced. Another mother who was using the Browns for short-term care said 'I could not believe that anyone else would change my son's nappies for me. She is just an ordinary mum, too, like me, living in an ordinary house down the road, not a nurse or a teacher, just an ordinary mum—that, to me, is terrific'.

Mr and Mrs Brown did not think that handicapped visitors should be imposed on their own children without their consent, otherwise they might resent them, so they had discussed the scheme with their two sons before they started and had got their agreement to it. The boys' favourite visitor was a totally helpless nine year old cerebral palsied girl, who was very tiny for her age. Mr and Mrs Brown did not know whether this was because the little girl, being so physically incapacitated, posed no threat to them, or because they found it easier to understand her handicap as it was so visually obvious; they found it more difficult to accept children who looked normal and behaved abnormally.

Mr and Mrs Brown knew that their sons were interested in the scheme and liked having the children to stay. They had recently heard them sticking up for handicapped children when one of their friends was making derogatory remarks about 'spastics' and 'mongols'. But they thought it was difficult to accurately gauge what their sons really thought about it, and they wondered whether special foster parents might be under-estimating the effects that the scheme could be having on their own children. As special foster parents want the scheme to succeed and want their own children to be accepting and kind, there could be a danger that they will not recognise some of the ambivalent feelings that their own children might have about the visits of the handicapped children.

The Browns felt that one disadvantage of the scheme was that it restricted social life. This restriction had not been very apparent when they first started, but as the time went on they began to feel that their lives were curtailed when they had the children to stay; they did not go out so often to the shops, parks, and church. This was not necessarily because the children were unacceptable in the neighbourhood, but the sheer effort of getting them out was sometimes difficult and tiring.

The Browns gave approximately six months of the year to the scheme. They did not feel that they could give any more time than that, but social workers were not making it easy for them to stick to this generous commitment. And some of the families, as well as social workers, were putting pressure on them to take their children more frequently. This made them feel that the success of the scheme was, in a way, its undoing—the more successful they were at supporting families then the more pressure they seemed to get from people wanting them to increase the help they were giving. In summing up what they felt about the scheme after working on it for more than two years, the Browns said that what they most disliked about it was the increasing pressure put on them by social workers trying to push them beyond their commitment.

'The difference between working in a hospital . . . and looking after children at home is unbelievable.' (Special short-term foster mother.)

Mrs Queen was a qualified mental handicap nurse and had worked for ten years in mental handicap hospitals before she married and had a baby. Mr Queen was a community mental handicap nurse based at the local psychiatric hospital. They heard about the special fostering scheme through a parents' meeting attended by Mr Queen. They applied because Mrs Queen thought it was a job she could do now that she was at home looking after their own one year old child. They also wanted to be associated with the scheme because they thought it was a means of keeping children out of hospitals, and a good example of what community care should be about.

They concentrated on taking very dependent multiply handicapped children rather than mobile active ones, partly because they fitted in better with their own small child and partly because Mrs Queen had always worked in wards for cerebral palsied children and particularly liked looking after them.

Before she took her first child Mrs Queen wondered whether she would be able to cope with handicapped children in her own home and taking 24 hour responsibility for everything they did and needed. She knew she would have only one handicapped child at a time at home whereas she had often had more than 20 at a time when she had worked in hospitals, but in a hospital there were always other staff to call on if necessary. However, her worries about 24 hour responsibility disappeared once the children started coming, and she decided that having one child at home compared to a whole ward full in hospital was just 'a piece of cake'.

What Mr and Mrs Queen liked least about the work was seeing some children returning to poor conditions after having stayed with them in their comfortable home for a week or two. They had taken several children who, as well as being mentally handicapped, came from families who had problems due to poverty and bad housing, and Mrs. Queen found it difficult to accept the standards of some of these families and the fact that if she taught the children something when they were staying with her their natural parents might not necessarily keep it up because their energies were exhausted by the struggle of day-to-day living in bad housing.

She found it very satisfying to have the children as part of her family life, all sitting down to eat together and going out to the shops and park as a family. She recalled that when she was working in hospitals, she had often wished that she could take a child home with her for a weekend, but she never could, and if they went out it was in a large group in a minibus and there was no opportunity for individual caring. 'The difference between working in a hospital, with all its restrictions, and looking after the children at home is unbelieveable' she said. She especially liked the contact with parents. One mother had come to see her three times before her child stayed overnight. Each visit had lasted over two hours and she had left a notebook containing a list of her child's likes and home routines and what he played with and how he was put to bed. Mrs Queen found this shared caring of the child very rewarding.

After working on the scheme for two years Mr and Mrs Queen thought the best thing about it was the satisfaction they felt through helping the families. When working in mental handicap hospitals they had enjoyed their contact with colleagues but they had never had any real job satisfaction because they always had to work in crowded wards and could not give the children sufficient individual care nor make contact with families. Now, with Mr Queen working as a community nurse and Mrs Queen caring for children in their own home, they felt that they were both enjoying a full professional life as well as a happy home life.

'The only trouble is, the parents think it is forever.' (Special short-term foster parents.)

Mr and Mrs Lobb had been registered foster parents for eight years. Mr Lobb did not have a separate job. They had always worked together in looking after children and had regarded themselves as professional partners in foster care. Before the special scheme started they had occasionally fostered a handicapped child as part of ordinary fostering. As soon as they heard about the special short-term scheme being set up they asked the social services department if they could transfer to it. They were in their mid-30s and had four children of their own, aged from ten to five years, when they started on the scheme.

Mr and Mrs Lobb went on several training visits to hospitals and schools and had a talk from a paediatrician and a psychologist before they took their first short-term foster child. They found the visits and talks very helpful. Their biggest worry had been the thought of a child having a major epileptic fit, but this had never happened. The feeding of the cerebral palsied children sometimes presented problems but they usually found that this eased off once they got to know the child. 'You've got to watch the children's eyes and faces and try to guess what they are thinking about and remember they must be feeling just as worried about us as we are about them. Once we get to know each other things usually settle down fine.'

Like other special foster parents they found it helpful when parents came for several visits and stayed for a few hours to talk about their children and get to know the house and family. They always liked the parents to give them the fullest information possible and did not think that any detail about the child could be considered irrelevant. One mother had not told them that her child was prone to serious nose-bleeds and they had been alarmed when he had a bad nose-bleed the second day he was with them.

Having the children to stay had not caused any changes in the Lobb family life. Caring for a big family and having a house full of children was their normal life-style and this continued the same whether or not they had a handicapped child staying with them. They believed that their own children liked having the handicapped children to stay, although they seemed puzzled about why the cerebral palsied children did not play with them and sometimes could not speak, and they asked lots of questions about 'what made them get handicapped'. Like other special foster parents, the Lobbs had some reservations about the effects of the handicapped children's visits on their own children. One of their children, like Mr and Mrs Roche's daughter (see page 213) had been very upset about one of her favourite toys getting broken by a very over-active handicapped boy and, although she accepted their explanations for the incident, they felt that perhaps there were more strains for their own children than was generally acknowledged by the organisers of the scheme.

Mrs Polani, the mother of two very handicapped children was being regularly helped by Mr and Mrs Lobb. Her children had been staying with them for two weeks every nine weeks for more than two years. On their first visit they were very tense and kept asking. 'Where mummy? Where mummy?'. Mr and Mrs Lobb had been very thankful that their mother had phoned up every evening to talk to them. But they had not been so homesick on subsequent visits and they gradually began to call Mr and Mrs Lobb 'Uncle' and 'Aunty' and obviously felt confident and happy with them. They always left a doll and a handbag sitting on a shelf in the Lobb's kitchen to await their next visit. This element of continuity—toys waiting for them to come back, sleeping in the same bed each time, the family mealtimes in the homely kitchen, must have given them a sense of security.

After working on the scheme for three years the Lobbs said they did not want to give up completely but felt they needed a rest from the constant 'giving out' which the work demanded. In retrospect, they thought that having been very eager to help they had probably over-committed and over-stretched themselves in the early stages and were now almost trapped by their own goodwill towards the families and children. They did not think that social workers protected them enough from the demands of the work. In some ways they wanted to have a break from the work, but at the same time felt that they could not give up or ease off because they did not want to let down the parents and children they had grown fond of. 'The only trouble is, the parents seem to think that it is forever' they said. Indeed, it was plain that most of the parents of the handicapped children tended to shut their eyes to the fact that one day their special foster parents might want to partly or completely give up, or be forced to give up for some reason such as moving house or illness in the family.

'I'd picket their house if it was going to be demolished or if they were told to stop fostering', said Mrs Polani.

'We'd never let Nancy go to anyone else' said the Smith family. Nancy, their tiny cerebral palsied daughter had been staying regularly with the Lobbs every few weeks for two years.

These were typical of the remarks made by parents whose children stayed with Mr and Mrs Lobb. But although they were glad to know that they were helping, and although they were genuinely fond of the parents and children, that level of expectation and dependence sometimes struck them as an almost intolerable responsibility. Like Mrs Erikson (page 212) and Mr and Mrs Brown (page 222) they sometimes felt that they had over-committed themselves, and they were worried by the emotional problems which seemed to be gradually building up on them. The public interest they had received when they first started, with articles about their work in the local press and interviews on radio and television had been stimulating and exciting, but after nearly three years doing the work they felt that what they now needed was some support for the emotional problems that were occurring because of the dependency of the families they were helping. The faith of the families was almost frightening and made them feel over-awed by responsibilities. 'The practical things are nothing. We start off being worried about nappies, wheelchairs, fits and drugs. But later on, when you've grown fond of the children and their parents and want to continue helping them, you feel almost that the demands are getting too much for you and then you need some sort of help yourself. But social workers don't seem to appreciate this, they are always busy fitting children in and finding places for them, and once the introductions have been made you do not see them again to talk to about the problem of being relied on too much.'

The death of a child who had been regularly staying with them had caused them immense grief. He had been taken ill in his own home and been in hospital for a week before he died. His parents had kept in touch with them throughout his illness and telephoned them an hour after he died. It was the first time in their lives that Mr and Mrs Lobb had experienced the death of a child and they did not know how to cope with the pain of it. They felt dreadfully upset that the professionals, who had encouraged the affectionate relationship to develop between them and the little boy, did not seem to appreciate the extent of their bereavement.

'It has never been mentioned, how upset we felt about him dying. It should have been told us in the beginning that some of the children could die, but nothing was ever said . . . and nobody wants to talk about it now, either.' They attended monthly meetings of special foster parents organised by social workers, but the death of the little boy had not been referred to at any of the meetings. They could not explain what sort of help they would have liked for their grief, but they just knew that they felt very bereft and were hurt because it did not seem that any of the professionals understood or cared that they were sad and needed an opportunity to talk about what had happened. They said they still had his name written in their booking notebook for the coming year and whenever they looked in the book and saw his name and the dates of his planned visits they were reminded that he would never come to them again. A few weeks after he died they were approached by a social worker who, knowing they now had a vacancy, hoped to fill his dates with a new child. They had been very upset by this. The last thing they wanted was a social worker immediately trying to fill the dead child's place with a new child.

Perhaps the impact of the child's death on the Lobbs was denied because the professionals wanted to think that the scheme was always very positive and always brought happiness and satisfaction to everyone. In the pioneering of a new idea there may be a tendency to highlight its positive aspects and deny any negative aspects, and this may have been one of the reasons why it was difficult for the professionals to recognise and acknowledge that the scheme had actually caused one of the special fostering families as much grief as happiness.

Discussion

It is important to note that special fostering schemes are being used not only for mentally handicapped children who are able, mobile and easily manageable, but also for children who have behaviour problems or very grave multiple handicaps. The schemes appear, indeed, to have effectively squashed the myth that some children have to be cared for in hospitals because they need 'medical and nursing care'. The special fostering parents, like the children's own parents, may not have had any medical or nursing training but, with appropriate advice, they have leant to manage very severely handicapped children in their own homes. One feature of the schemes, although this was not originally intended, is that the special fostering parents sometimes 'specialise' in taking children with particular difficulties. For example, the Browns and the Roches liked having children who were active and had some degree of behaviour problem, the Lobbs and the Queens liked to have cerebral palsied children, the Eriksons had a particular interest and skill with deaf children, and Mrs West liked to have younger active children or more placid teenage girls. Significantly, out of the six special fostering families referred to in this chapter, only Mr and Mrs Queen were registered mental handicap nurses; the other five had learnt to manage by getting to know the individual children and finding out their needs from their parents.

The stories of the six special fostering families and their work drew attention to some of the advantages and the pitfalls of the schemes. These are discussed in a little more detail as follows.

Advantages for the handicapped children

Staying with a special short-term fostering family enables the children to have short-term care in an ordinary home environment instead of in the abnormal environment of a hospital or hostel where, no matter how careful the staff try to be, the children are bound to see other children and parents constantly coming and going and bags being packed and unpacked. In this abnormal atmosphere of transit they are never quite sure whether their parents will fetch them today, tomorrow or next week, and some of them get distressed and need repeated reassurances and countings on fingers about when their parents will be fetching them and how many more nights it will be until they go home. This transit atmosphere does not occur in special foster families.

Another advantage is that the special foster parents are not having to care for large numbers of children and do not have set duty hours, so they are able to give the children more individual mothering and continuity of care than is possible in hospitals and hostels where the staff have many children to look after and are constantly changing because of their duty times. It was noticed that in special foster homes the children had their own toys, continued to have ordinary family routines, they were touched, talked to and cuddled, and were welcomed back warmly from school. They did not have to compete for attention, and they did not mill restlessly around looking out of the windows and ceaselessly going from adult to adult asking when they were going home and where their parents were, which was a common and constant behaviour pattern observed amongst the children receiving short-term care in residential facilities (see Chapter 7).

The integration factor

When children have short-term care in special foster families they remain in an ordinary house in an ordinary neighbourhood, but if they go to a hospital or hostel, even if it is sited in a town, they are inevitably segregated into a special and separate place. The integration of their handicapped children into ordinary families reassures their parents that society is not entirely hostile and rejecting. For handicapped children without brothers and sisters the schemes may be the first opportunity they have ever had of meeting and living with non-handicapped children. Mrs Carter (see pages 103 and 220 whose son Paul was having short-term care with Mr and Mrs Brown said, 'Staying with the Browns and their two boys has given Paul a chance to mix with ordinary children for the very first time in his whole life'.

Another aspect of the integration factor is that it helps to spread understanding of handicapped children amongst the neighbours and relatives of the special foster parents who, perhaps for the first time in their lives, will get an opportunity to meet and know handicapped children as children instead of thinking of them as members of an amorphous shut-away group labelled mentally handicapped. Special foster parents referred to neighbours' prejudices about mental handicap being broken down by their meeting the short-stay children, so it would seem that the schemes are as beneficial to those who are not handicapped as it is to those who are.

The special foster parents' own children are also part of this integration process. According to some of the foster parents, their own children were helping to change the attitudes of other young people: 'I heard my two kids sticking up for handicapped people', and 'My children's friends have got much better attitudes since meeting the handicapped kids here at our house' were typical remarks being made by special foster parents about their own children and their friends.

The children of the special foster parents

The special foster parents who were met during the study said they had talked to their own children about the schemes before starting the work and they did not resent the visits of the handicapped children but participated in their care as they would with a natural brother or sister who needed extra help. In some areas they had even received a sort of introductory training, being encouraged to work as volunteers in local hostels and special schools before the children started coming to stay with them. From the views expressed by the special foster parents it seemed that the schemes held some very positive aspects for their own children: for example, they liked having the handicapped children as additional companions; they enjoyed helping to look after them; and because they shared their homes and parents it helped them to develop altruistic feelings towards handicapped people.

However, there is a need for some careful research to be done into what the children of special short-term foster parents really think about handicapped children coming to share their family life every few weeks. It would seem that very little is yet known about whether or not the visits cause any strains for them. They may seem to be very accepting and tolerant about the visits, and may even find it easier to have a handicapped child to stay than a normal child who may create more rivalry, but, with no firm evidence available, one should be very wary of making assumptions that the visits are always a very positive experience for them and that they are always willing to share their homes and parents with handicapped children and always happy to make allowances for the very difficult behaviour of some of them. Making such blanket assumptions merely sentimentalises the schemes.

One popular assumption is that having mentally handicapped children to stay makes the children of the special foster parents grow up with very positive attitudes towards handicapped people. However, this has not yet been proved; indeed, it is possible that they may grow up with quite negative feelings towards less able people because having other children to share their homes and parents' attention gives them resentful memories which are connected with, although perhaps not directly caused by, the fact that the visiting children were handicapped.

Three issues emerged from discussions with special foster parents. First, their own children inevitably get less attention when the handicapped children are visiting. Whether or not they are affected by this reduction in attention will probably depend on their ages and needs at the time. For example, five year olds starting school and teenagers studying for O and A level examinations may well resent having to share their parents' attention with a visiting handicapped child, but at less stressful periods in childhood and adolescence they may wholeheartedly enjoy the visits. Bearing this in mind it may be advisable for special short-term foster parents to lessen their commitment to the schemes at critical periods in the lives of their own children.

Second, some of the children cried when the handicapped children left. The special foster parents did not think that these tears were anything to worry about; they regarded them as evidence that their own children cared about the handicapped visitors and made a warm relationship with them. However, it is possible that some of them may be left feeling very upset and unsettled by the repeated departures of the handicapped children after having been encouraged to be very friendly and involved with them. Perhaps not enough thought has gone into this aspect of the scheme. The children of the special foster parents need to have very carefully spelt out prior explanations about why the handicapped children do not stay for long and keep coming and going.

Third, the death of a handicapped child is likely to be very distressing for the special foster parents' own children. Again, perhaps not enough thought has been given to the painful likelihood that a death may occur amongst some of the handicapped children who are very frail and have deteriorating conditions and, if it does, all members of the special foster family will feel saddened.

The doubts expressed in this section suggest that the schemes may have some negative aspects for the children of the special foster parents. Perhaps they have ambivalent feelings about the visits of the handicapped children. Perhaps they are not expressing their real feelings about the schemes because they know that their parents want them 'to be good' and to welcome the handicapped children and willingly share their homes and parents and toys with them; perhaps the emotional pressures of living up to their parents' expectations that they will be very unselfish may be quite a problem for them, and one which they cannot easily express. Their true feelings about having to compete for their parents' attention, and share their bedrooms and toys and outings, may be underestimated because although their opinions have ostensibly been asked for, these opinions have been unintentionally falsified because of their parents' expectations of altruism.

Further research may show that the schemes have definite advantages for the ordinary children as well as for the handicapped children, which far outweigh any disadvantages. But until this is evident it would seem unwise to make assumptions that everything about the schemes is entirely positive.

The friendship factor

Chapter 5 drew attention to the poor contact between parents and staff of residential facilities; the initial introductions of parents, children and staff were too casual, and the staff did not seem to realise that continuous friendly contact with the parents was an essential part of the short-term care of their children. Some parents who had been regularly using a residential facility for over two years did not know the names of the care staff. In fact, the development of a happy relationship between the parents, the children and the staff of short-term residential care facilities seemed to take second place to the very basic idea that the children were given a bed and thereby their parents got a break. One social worker said that when she was placing a child in a hospital for short-term care she did not give much attention to introductions, nor encourage the development of good relationships between the staff and parents. In some cases it was possible that the parents did not meet the hospital staff before the children went in for short-term care, but, in contrast, when she was arranging for a child to have special short-term fostering, she would spend considerable time making sure that the children and their parents were familiar with the special foster parents.

One of the characteristics of special fostering is the friendly atmosphere between the natural parents and the special fostering parents. This is encouraged by the professionals organising the schemes, who recognise that it is important for the two families to know and like each other before the children have their first overnight stay. In some cases the families become personal friends and meet each other in between the children's periods of short-term care. 'We are close friends now with the Murphys, since we've been looking after their son. Making friends is part of the scheme', said Mrs Erikson after working on the scheme for two years. 'She is the finest friend that we have ever had' said Mr Scott about Mrs West, who had been looking after his daughter for short periods over two years.

Only one of the special foster families who were met during the study said they disliked the friendship factor. This couple, like Mr and Mrs Lobb, had been fostering ordinary children as registered foster parents for over ten years before transferring to the special scheme. But, unlike the Lobbs, they did not like the idea of making friends with the parents of the handicapped children, and felt that this was a side of the scheme they could not cope with after working so long in ordinary fostering where they were not encouraged to make friends with parents nor even expected to meet them. 'The obligation to be friends with the parents of the handicapped children is how the special scheme differs from ordinary fostering and what we dislike about it', they said.

'We are not used to it. We like the kids but have no wish to be friendly with their mums and dads.' The reactions of this couple were unusual. Other special foster parents (whether they came from ordinary fostering or had been newly recruited for the special schemes) believed that friendship with the children's parents was a very important part of the service.

The dependency factor

It is difficult to define exactly how and when the friendships which are an integral part of the schemes and such a joy, sometimes become a fraught and anxious over-dependence. The problem of over-dependency stems from the advantage that makes the scheme such a unique form of support—the warm relationship between the two families. So, ironically, the more successful the relationship is between them, the more likely they are to suffer worry and anguish if anything happens which threatens to end the friendship or does actually do so. If the special foster parents have to give up, even for an understandable reason such as moving house or an illness in the family, they may feel very guilty about letting down the families they have been helping, and the natural parents may feel very rejected. Worries about losing the help of their special fostering parents were expressed in remarks like the following made by some of the children's parents.

> 'I worry all the time in case Mrs . . . gets overtired and has to give up.'
>
> 'I dread that her husband will get promotion and they will have to move out of the district.'
>
> 'I've heard that Mrs . . .'s mother is poorly and they might have her living with them, and then they will have to stop doing the short-term fostering. I simply dread this happening.'

For some parents the withdrawal of help from their special fostering families can be almost as traumatic as a bereavement, and may leave them feeling so rejected that they do not want any more of such help ever again.

> 'When they moved I was absolutely shattered. I never wanted to make a friendship like that again; I decided to use hostel care in future—in that way I would not get hurt because I wouldn't become friends with the hostel staff like I had been with Mrs . . .' said one mother whose special fostering family moved out of the district after having helped her regularly for over two years.

Parents' anxieties about the possibility of the relationship coming to an end are equalled by the anxieties felt by the special fostering parents as they gradually realise that the relationship which the professionals encouraged them to develop with the children's parents is in danger of becoming all-consuming. 'They think it is forever', said Mrs Lobb (page 225). After three years as a special foster parent she was disturbed by the responsibility of the growing dependence of the families she was helping.

It appears that some professionals, after encouraging the development of friendship between the families, are not recognising the emotional pressures that may be put on the special foster parents when the children's parents become over-dependent on them. The present way in which the special fostering is organised—with good introductions and both parties being supported in the first stages of meeting each other but thereafter being left to develop their relationship as they wish—leaves too many loose ends and may mean that problems of over-dependency are never properly recognised and examined. In the early stages of starting the work the special foster parents may over-commit themselves through enthusiasm and an eagerness to help, and it is at this stage that they may need particular help from the organisers. Some of the problems of over-dependency might be avoided, or at least faced up to, if special foster parents were encouraged to discuss their commitment when they first start. For example, initially giving a limit to the length of time they will commit themselves to working on the scheme—perhaps saying not more than one year. This initial commitment would be reviewed at the end of that time and, after review, they may well want to continue for another year. But the very fact that a limit was initially set will orient their thoughts and the thoughts of the natural parents to the fact that the scheme may not necessarily be forever. A contract, no matter how often renewed, serves the purpose of acknowledging a likely limit and thereby helps to give an emotional escape route.

It is when special foster parents do not see any limits on their commitment that some of them begin to feel overwhelmed, and even exploited, by social workers and families who want to make increasing use of their help. And the more successful they are at the work, and the more willing they are to commit themselves to it, the more likely they are to have emotional pressures on them, which may eventually exhaust them and force them to give up.

In addition to early discussion about limiting the length of time they may be able to work on the scheme, other ways to ease the problems of over-dependency might be to limit the number of weeks in the year that they will provide short-term care, to have discussion with the organisers at group meetings and individually about the value and pitfalls of friendship and dependency, and for the organisers to occasionally arrange for a stand-in family.

The anxieties which over-dependency causes—for example, the natural parents' fears that the fostering parents will one day give up, the foster parents' worries that they may *have* to give up or *want* to do so, and the effort of responding to the demands put upon them—ought not to be inevitable problems with the special fostering schemes. They have developed into problems because the social workers who initially encourage the relationship fail to give continuous support to its later development and are not readily available when problems of over-dependency arise.

Social work support

In some local authorities the schemes are being organised from the ordinary fostering departments. This may not be very satisfactory because, although the two types of fostering are alike with regard to child care principles, each also had its very different needs, and as ordinary fostering is often concerned with family crises or child abuse it is inevitable for problems in special short-term fostering to be seen as relatively less urgent. In some areas the schemes are run jointly by the local social services departments and voluntary organisations (for example, local branches of the Royal Society for Mentally Handicapped Children, the Cheshire Foundation, Dr Barnado's, the Invalid Children's Aid Association). The voluntary organisation takes on the responsibility of recruiting and training special fostering parents and for introducing the families to each other , whilst the social services departments provide the finance and some support from generic social workers or their ordinary fostering department.

Some local authorities have appointed a social worker to be especially responsible for the organisation of special short-term fostering. This would seem a wise decision. It is not altogether satisfactory for the service to be added to the caseload of generic social workers or ordinary fostering officers because they are likely to regard the organisation of the families' initial introductions as the main task and have little subsequent involvement apart from 'keeping an eye' on later bookings between the two families, ensuring that payments are going through, and support services (such as nappy supplies and school transport) are running smoothly.

Weaknesses in the social work support of the special schemes arise partly because generic social workers carry immense caseloads concerned with every type of family crisis (for example, child neglect, elderly people, mental illness, homeless families), and partly because they assume that the special foster parents recruited for the schemes are mature, stable people who have no other problem except learning how to care for a handicapped child in their own home, and who are capable of building up relationships with the families they are helping without any interference from social workers. They fail to recognise that after the schemes get started certain problems such as over-dependency and the death of a child may develop and need skilled social work support.

The grief of Mr and Mrs Lobb was referred to on page 226 regarding the death of one of their special short-term foster children; their grief was not recognised nor helped by the social worker who had been initially responsible for introducing the two families. Different families will, of course, react in different ways to the death of a special foster child, but they are certainly experiencing a bereavement and the first concern of the professionals should be to acknowledge that bereavement and offer appropriate help in a sensitive manner; the social worker should visit and give them an opportunity to talk about the loss, and they should not be immediately offered a 'new child' to 'replace' the dead child.

Mrs Roche was distressed when she saw the severe deformities of a small cerebral palsied child for the first time (see pages 215 and 216) but she did not have any opportunity to discuss her feelings with anyone, and she became so saddened about the problems of cerebral palsied children that she decided she could not take them any more. Again, this was a problem which may have been helped by sensitive discussion with a social worker.

Another special foster parent was upset by what she thought was her failure with a handicapped child who had a behaviour problem. When he threw his dinner at the wall she felt guilty about her 'inability to cope' and her wish that the child should not come to her house again. However, she continued to take him and gradually overcame her dislike of him and they finally developed a good relationship. But she managed her problem alone because she did not like to discuss her angry feelings with the child's parents and she did not receive any support from a social worker who might have been able to point out to her that her continuing acceptance of this very difficult boy was ample evidence of her ability to cope and her wish to help his parents. It is possible that some special short-term foster parents may be permanently lost to the service simply because they do not receive help with a problem nor do they successfully manage to work through it on their own as that woman did.

Pertinent questions are: do social workers see their task only in terms of bringing two families together and then withdrawing—having merely a gift relationship with them (that is, 'I will give you this gift. A family who will help and befriend you and share your child's care'), or do they see their task as giving continuous support to both families as the relationship develops?

Social workers often describe the schemes in such terms as 'We are not needed', 'These families are not problem families', 'The schemes take off, they run themselves really'. The 'taking-off' occurs because the two families are encouraged to build up relationships which are independent of professionals—they make their own dates for the children's visits, they have their own chits for payment, they often meet socially. But at what point should social workers step in and offer advice, or even casework skills, to families who are, after all, considered stable and without any problems requiring social work support in a traditional sense? Is it possible, indeed, for overworked generic social workers to take on the many subtle problems that may arise in special short-term fostering some time after the initial introductions have been successfully made?

The problems that do occur are mainly caused by distress over children's severe handicaps, inability to cope with behaviour problems, the unexpected death of a child, the children's parents becoming over-dependent, loss of friendship and support when the special foster parents have to give up for some reason such as moving house or an illness in the family. The issues are subtle and the problems may seem negligible in comparison with the many other more dramatic and urgent problems that social workers have to deal with, such as child abuse and homelessness; for this reason it would seem advisable for a special social worker to be responsible for the schemes, somebody who would have the time and insight to support their special needs, rather than tacking on the responsibility to the social workers of the ordinary fostering department or to generic social workers.

Group meetings of special foster parents

In some areas the social workers arrange for the special foster parents to meet regularly, as a group, to discuss the work they are doing. But these meetings may do little to solve the problems referred to in this chapter.

One reason group meetings don't succeed is that a gap often exists between the newest foster parents and those who have been working on the schemes for a year or more. The latter seem to need a very different form of discussion from that which satisfies the former. The social worker in one borough arranged for all special foster parents to meet one morning a month to discuss any problems that were arising; the group included parents who had only just started doing the work, as well as those who had been doing it for at least two years. After a while the more experienced ones became very dissatisfied with the meetings and felt that the level of discussion was not very helpful; they were irritated because the newest special foster parents wanted to talk only about their first experience of having a handicapped child to stay with them, and tell amusing stories of their first few days getting to know a child with a behaviour problem or how to manage a cerebral palsied child in the bath for the first time. It was obviously helpful for the less experienced special foster parents to be able to talk about their experiences of beginning to work with handicapped children, but the meetings tended to concentrate on these issues and did not allow for discussion of the problems caused by deepening relationships with families and the way in which these occasionally threatened to overwhelm them. Eventually, as the content of the group discussion did not satisfy the more experienced special foster parents they regarded them as little more than pleasant coffee mornings.

Perhaps meetings should be more structured and even have a programme of topics, such as:

1 The place of handicapped children in society; the philosophy of community care; how the special fostering of handicapped children is a means of changing neighbourhood attitudes.

2 Personal reactions to children's very severe deformities; coping with one's feelings of distress and inadequacy when faced with a child's severe handicaps.

3 The reactions of the special foster parents' own children to having a handicapped child to stay.

4 Should special foster parents get involved in teaching the handicapped children and following programmes, or should they aim only to give general family-style care? Can the teaching of skills be combined with family-style care?

5 Communication techniques, such as Makaton, Paget-Gorman signing system, Blissymbolics, lip-reading. The special needs of blind and deaf children.

6 The role of other professionals, such as teachers, psychologists, physiotherapists, occupational therapists, speech therapists and doctors, in special short-term fostering schemes.

7 What do special fostering parents expect of the social workers who are responsible for organising the schemes? Do they want continuous support or just help with preliminary introductions? Coping with professionals who put pressure on them to increase their commitment to the scheme.

8 The problems that can arise in a relationship which becomes increasingly dependent; how to manage the relationship; learning to say 'no' if necessary; coping with having to let down a family because of moving house or illness in one's own family; coping with parents who put pressure on them to increase their commitment to the scheme.

9 Should special short-term fostering continue after 16 years old? Not all special foster families want to stop their contact with families when the children reach school-leaving age, but they may have to do so because the terms of the fostering scheme relate only to helping children up to the age of 16.

10 The death of a foster child; coping with personal grief and the fear that this will happen again.

11 Training to be a special short-term foster parent. What sort of training is needed? What did they find most helpful in the beginning and what are their needs after working on the schemes for more than a year?

Discussion of the above issues, as a group, would not only help the special foster parents but would also help the professionals to sort out some of their ideas about the schemes.

Training

In most areas the special foster parents are offered some type of training before they start taking the handicapped children, even if they have worked with handicapped children through previous employment. The training often consists of explanations about mental handicaps, its causes and problems, visits to special schools and hospitals, advice about feeding cerebral palsied children, lifting, dressing and bathing very dependent children, coping with behaviour problems. Sometimes there are lectures from social workers, teachers, doctors, psychologists, physiotherapists and speech therapists.

Special foster parents who have not had any previous experience with handicapped children are usually anxious to get information about mental handicaps and different syndromes, and they seek advice about the practical care of children who might be difficult to manage and communicate with. They often want detailed explanations about specific medical problems, especially epilepsy. Initial worries about epilepsy are very common, but most special foster parents later find that this is not the problem they had anticipated because carefully prescribed modern drugs have reduced the frequency and severity of children's fits. Most special foster parents who have no previous experience of handicapped children find it helpful to have talks from professionals and visits to schools and hospitals. But some feel that this sort of training concentrates too much on the difference between handicapped children and non-handicapped children and they think that it would be better to draw more attention to the similarities.

After the special foster parents begin their work and get to know the children they generally feel that if they want any further information or advice this is best obtained from the children's own parents because what they want to know is usually concerned with the needs of an individual child rather than with general aspects of mental handicap. This might imply that there is no need for special foster parents to have any training other than a few preliminary visits to special facilities and some lectures from professionals on basic general information about handicapped children. However, there is a need for some *planned* continuous support in addition to basic training; this could be through regular meetings of special foster parents (with or without the children's parents) when topics such as those listed on pages 237–238 might be discussed.

Conclusion

Special short-term fostering began with the advantage of attracting enthusiastic professionals who were committed to the development of community care and also not afraid to innovate new ideas. It soon proved a valuable form of help, and other authorities began to copy the example started by Leeds and Somerset. It is likely that the majority of local authorities will have the service by the end of the 1980s. Hopefully, it will then be available to all parents who want this type of occasional help in caring for their handicapped child. However, it would also seem important for the schemes to now be carefully and critically monitored at national and local level, in order to decide guidelines for those involved in its organisation and to prevent the repetition of mistakes and the likelihood of some incident occurring which might sadly discredit the service.

Footnote:

In 1982 a group of professionals working in special foster schemes in some districts in London and the South East began to meet regularly at the King's Fund Centre to discuss the principles and organisation and problems of the service. Reports by this working group should be a helpful contribution to the future development of the service. In 1983 the members of the group were: Margaret Phelps (Hounslow) Group Chairman; Janet Hughes (Merton) Group Secretary; Lesley Campbell (Camden); Peter Elfer (Croydon); Helen Hood (Dr Barnardo's, Southwark); Rosalind Walker (Haringey); Cathie Joyner (Canterbury); Lisa Lawrence (Lewisham); Judy Marsham (Sutton).

Appendix How one short-term care facility was used during a three-year period

The following discussion and figures refer to the use made of a 12-bedded short-term residential care facility. The facility evolved from the changing use made of a paediatric ward in an old fever hospital. The hospital had separate villa-wards (traditional fever hospital design) and as infectious diseases had declined through vaccination and antibiotics, its villas were gradually boarded up or used for a variety of non-acute services such as the long-term care of elderly people, for minor day surgery, dentistry, physiotherapy or for storage and adminstrative offices. This is a common way to make use of old hospitals in the UK. As the villa ward for young children with infectious diseases was no longer needed (those who did need hospital care being admitted to the paediatric wards of the general district hospital), it started being used for the short-term care of young mentally handicapped children and was eventually converted into a family help unit offering short-term residential care and occasional day care to families in the catchment area of the health district who had mentally handicapped children up to the age of 16. For the first three or four years following its conversion, the facility remained under the administration of the health district's paediatric services. It was then transferred to the mental handicap division.

The facility gave very helpful support to families (and was still doing so in 1983 when this report went to press), but its siting was definitely not appropriate for the residential care of children, nor was the layout of its accommodation. Although such places may seem to give a good service, it would be a pity if health authorities were to continue to give approval to the trend which became very popular in the 1970s and early 1980s of converting old health service properties such as ex-fever hospitals, out-dated maternity hospitals and buildings once used to accommodate nurses, into short-term or long-term living accommodation for vulnerable groups such as people who are elderly or mentally handicapped. These people need to live in ordinary houses with staff and community support services readily available according to their individual requirements. However, leaving aside the dubious philosophy of providing residential care on inappropriate old sites instead of selling the sites and putting the money into community services and ordinary housing, the following figures give a broad idea of how one small short-term facility was used by local families between 1977 and 1980.

The 12-bedded facility served a catchment area of 850 square miles covering a city surrounded by farmland with small villages and sparsely populated moorland. The total population of the area was 402 000. In the period 1977–1980 it was used as follows:

Number of children known to the facility but who had not used it for day or residential short-term care	30
Number of children using the facility for day care only	23
Number of children who received extensive short-term residential care which became long-term care (they were eventually found permanent placements elsewhere)	8
Number of children who received short-term residential care (some of these also used the facility for occasional day care)	113
Total number of children associated with the facility	174

The 113 children who received short-term residential care came from 107 families, five families having more than one handicapped child.

Ages at which the 113 children received their first overnight stay in the facility	Boys	Girls	Total
Four *months*	1	—	1
Eleven *months*	1	—	1
Between one and two years	5	—	5
Two years	4	1	5
Three years	6	6	12
Four years	6	2	8
Five years	4	—	4
Six years	4	2	6
Seven years	6	2	8
Eight years	2	6	8
Nine years	6	2	8
Ten years	5	2	7
Eleven years	5	3	8
Twelve years	10	1	11
Thirteen years	5	4	9
Fourteen years	7	1	8
Fifteen years	3	1	4
	80	33	113

The seven children aged under two years were frail and/or sick, multiply handicapped children who were admitted during 1977 when the facility was still in the process of changing from being a ward to being a family help unit, when it was still customary for the local paediatricians to admit babies with multiple handicaps to the ward if the parents seemed to need a rest. When the ward became a family help unit the admission of the children under two years old decreased, but those in the age group two to five years were still admitted and they totalled as many as 25 between 1977 and 1980.

Minimal users of short-term residential care

'Minimal users' describes children who used the facility for only one or two nights a year, perhaps because of a temporary need such as sudden illness in the family or because their parents wanted to celebrate an annual event such as New Year's Eve or their wedding anniversary.

There were 38 minimal users: ten girls aged between three and 15 years at the time of their first overnight stay and 28 boys aged between four months and 14 years at the time of their first overnight stay.

Their reasons for using the facility were: illness of parents or relatives; mother having a baby; moving house; attending a function (for example, anniversary, New Year's Day); need for a night's rest.

Six children in this group of minimal users were in the group of seven very young, frail and multiply handicapped children who were being admitted during the period when the facility was being changed from a ward to a family help unit.

The handicaps of the 38 minimal users	Boys	Girls	Total
Ordinary mental handicaps	18	8	26
Totally dependent (special care)	3	—	3
With severe behaviour problems	1	—	1
Not severely mentally handicapped	6	2	8
	28	10	38

The term 'ordinary mental handicaps' is used to describe the broad spectrum of mental handicaps, and the above group of 26 included six children with Down's syndrome and 20 others whose abilities ranged from being ambulant and fairly independent to non-ambulant and needing help with dressing, washing, eating and going to the lavatory. The 'totally dependent' (special care) children had very grave multiple handicaps caused by cerebral palsy, hydrocephalus, spina bifida, brain injuries, and were very helpless and totally immobile, some being frail and blind also. The eight children who were *not* severely mentally handicapped had very brief admissions before it was decided that the facility was not the appropriate place for them.

What happened to the 38 minimal users:

Six of the ten girls never used the facility again because:

3 reached the age of 16;
1 moved out of the area;
2 were not severely mentally handicapped.

The remaining four girls seemed likely to increase their use.

Nineteen of the 28 boys never used the facility again because:

2 reached the age of 16;
3 moved out of the area;
6 were not severely mentally handicapped;
1 was rejected by staff after one overnight stay, because he was thought to be a danger to other children;
4 did not come again because their parents did not want them to (reasons unknown);
3 died.

The remaining nine boys seemed likely to increase their use.

Regular users of short-term residential care

'Regular users' describes children making regular use of the facility, for example, every other weekend, one week in six, one night a week, one weekend a month.

There were 75 regular users: 23 girls aged between two and 13 years at the time of their first overnight stay, and 52 boys aged between 22 *months* and 15 years at the time of their first overnight stay.

Sixty-seven of the regular users lived within six miles of the facility; the other eight lived between six and 20 miles away.

Handicaps of the 75 regular users	Boys	Girls	Total
Ordinary mental handicaps	33	18	51*
Totally dependent (special care)	11	3	14†
With severe behavioural problems	4	1	5
Physically handicapped	4	1	5**
	52	23	75

* Includes 11 children with Down's syndrome.
† Includes one child with Down's syndrome.
** Children who had deteriorating physical disabilities and some mild to severe mental handicaps.

The reasons for the 75 children regularly using the facility:

unsuitable housing;
marital problems;
single parenthood (widowed, divorced, separated, unmarried and living alone);

a need for siblings to have more attention;
a new baby in the family;
chronic illness of parents;
a need for parents to have a regular rest;
father working away from home (in HM Forces);
parents wanting a regular night out together;
parents having elderly parents who needed help;
more than one handicapped child in the family;
multiple problems causing an accumulation of stress.

Regular users often had several reasons for using short-term residential care, and some of their reasons changed during the three-years; this was unlike the minimal users who usually had just one reason:

Family backgrounds of the regular users	Boys (52)	Girls (23)	Totals (75)
One or more siblings at home	48	18	66
Single parent carer	8	3	11
Another mentally handicapped child in family	2	3	5
Father in HM Forces	9	8	17
Mother suffering from depression (two of these were single carers)	1	3	4
Mothers with chronic physical illnesses	2	1	3
Father with chronic physical illness	1	—	1
Father with handicap of profound deafness	1	—	1
A chronically ill sibling in the family	5	—	5

The brief information given above, on reasons for regular use of short-term residential care and the family backgrounds, suggests that its regular use is in many instances associated with family life-style and/or family misfortune creating a situation wherein the care of the mentally handicapped child becomes difficult and requires some type of supportive service. For example, 17 regular users came from families where fathers were in HM Forces and away from home for long periods leaving the mothers virtually in the position of being single parents; 11 were from single parent families; ten had a mentally handicapped or chronically ill sibling at home; five parents had chronic illness or handicaps and four mothers suffered from depression.

After three years regular use:

Three of the 23 girls had ceased to use the facility because: two families had moved out of the district; and one girl (aged five) had gone to live permanently in a long-stay hospital as her family could no longer cope with her problems.

21 of the 52 boys had ceased to use the facility because:
two families had moved away from the district;
one boy aged 15 went to live in a long-stay hospital;
seven had reached the age of 16;
two stopped because their parents became dissatisfied with the care;
two died;
one went to a children's Home when his family broke up completely;
three went to live in Homes for physically handicapped children;
one stopped after older siblings in the family grew up and left home;
one went to a boarding school;
one was rejected by staff because of his very difficult behaviour when he was nearly 16 and had been using the facility for more than two years.

Children with behaviour problems

The number of children with really severe behaviour problems was very small; only five out of the 75 children regularly having short-term care. Other children went through a temporary period of behaviour difficulties, but these gradually quietened down. For example, some children had been labelled 'behaviour disordered' or even 'hyperactive' when they were aged three or four years old, but by the age of seven or eight they were no longer considered a problem. The children with behaviour problems appeared to fall into two groups: (a) the *temporarily* difficult children, usually aged six and under; and (b) those who might be described as chronically difficult, being older and larger and with problems in communication as well as being very active. As children with behaviour problems attract a great deal of attention when they are having short-term residential care, the impact they make on the service may unwittingly be exaggerated and some staff may come to believe that the facility revolves entirely around this demanding and worrying (but very small) group of children. This is common in most short-term care facilities, staff tending to assess the work of the facility according to the demands and needs of the most difficult children and their parents, so a myth grows that short-term care is almost entirely helping families with extremely difficult children. One would not wish, of course, to dismiss the problems of these children who have chronic behaviour disorders, but it must be noted that they *are* a minority of the total children being helped through short-term care and also that mentally handicapped children, like many normal children, may go through a temporary period of behaviour problems during their pre-school years and then become stable. (This is a time in normal child development when parents can experience difficulties with over-activity and demands for attention.)

Conclusion

The figures referred to in this appendix for this facility are very similar to those of others which were visited. For example, a facility of this size serving this catchment area and population will have approximately 200 children 'on its books'. Approximately half of these are likely to be regular users of short-term residential care; boys will outnumber girls; there may be more requests for short-term care just before a child reaches five and begins school (indicating that, like normal children, the handicapped children are likely to make more demands on their parents just before starting school); families in which the father's work requires long absences from home will use the support of short-term care, as will single parent families and parents with other handicapped or sick children at home or who are themselves chronically ill or handicapped; the numbers of children with very severe behaviour problems is small, approximately six in 100 regular users; and 'special care', very multiply handicapped children, will number approximately 15 in 100 regular users.

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Index

THEY KEEP GOING AWAY

The main theme of this book is the grief caused to some children with learning difficulties when they keep going away into short-term residential care so that their parents can have a rest.

> 'When I protested to the doctor and said Lara would not like it there, he told me that she was too handicapped to be aware of *where* she was so it did not matter where she went. "But she has feelings" I told him. The doctor did not seem to think she had any feelings at all and kept on and on to me about letting her go to Moor Grange and how she wouldn't know anything about it. So in the end I let her go. I felt I ought to obey. I did as I was told in the end. And I let her go. . . .'

Maureen Oswin describes the historical development of short-term residential care as a form of help for parents, relates parents' opinions of it, gives a very critical but sympathetic picture of the problems facing untrained staff caring for homesick children, and lists guidelines on how to achieve better standards of child care. She also discusses the early family-based respite care services which were pioneered in 1975.

The reissue of this book, which was first published in 1984, comes at a time when the 1989 Children Act gives hope that the 1990s will see improvements in residential care services for children with learning difficulties.

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