King's Fund Centre

ISSUES AND PRINCIPLES IN THE DEVELOPMENT OF SHORT TERM RESIDENTIAL CARE FOR MENTALLY HANDICAPPED CHILDREN

Maureen Oswin

King's Fund Centre,
126 Albert Street,
London NW1 7NF

February 1981

KFC 81/41

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

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

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A Discussion Paper

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PREFACE

Between 1977 and 1980 the King's Fund supported a study by Maureen Oswin of the ways in which short term residential care services for mentally handicapped children are being developed by different agencies and in different parts of England. This study was undertaken, with advice from the late Professor Jack Tizzard, at the Thomas Coram Research Unit. Because of the interest aroused by this work and the evidence that in many parts of the country staff and parents are actively considering how to establish or improve short term care services, the Fund has now provided support for a fourth year of this work designed to encourage local discussion and use of what has emerged from Maureen's observations. Thus during 1981 Maureen working with us at the King's Fund Centre (particularly with my colleague Joan Rush) in contributing to a series of meetings and discussions - some in London and some in various parts of Britain - where people concerned with these issues can come together to examine the principles which should inform the development of short term residential care and exchange views on how local progress towards better services can be made.

Maureen is writing up the results of the main study for publication in book form at the end of 1981. In advance of the book however, the Centre is publishing this paper which is a revised version of the talk Maureen gave at our first workshop on this topic in October 1980. The paper is intended as a discussion document for the local meetings during 1981 and also an intrim report on the study for other people who may be interested. As such, we hope the paper will be read critically and used as a stimulus for fresh thought and debate among planners, providers and consumers of short term care.

People who wish to pursue issues arising from this paper further will be welcome to contact Maureen or Joan at the address given on the previous page of this paper.

January 1981

David Towell

INTRODUCTION

The idea behind the provision of short term residential care services for mentally handicapped children is that families can have a welcome break from a child who may be causing strains in family life because he is difficult to look after. Depending on what residential facilities are available, the child may be placed for short periods in a local authority hostel or a voluntary society home, a mental handicap hospital, the paediatric ward of a general hospital or in a foster home. The frequency and length of the placement may vary according to the needs of the family, or again, on what is available. It may be a two-week placement when the rest of the family are going away on holiday in August, an occasional weekend, regularly arranged weeks throughout the year, one night every week, or even as much as a month away followed by a month at home all the year round.

The majority of the documents on mental handicap services which have been issued by the DHSS, local authorities, area health authorities and voluntary organisations over the last ten years have emphasised the value of short term care as a form of family support and recommended an increase in the service. The National Development Group Pamplet No 2 'Mentally Handicapped Children: A Plan for Action' and Pamphlet No 4 'Residential Short Term Care for Mentally Handicapped People: Suggestions for Action' both describe short term care as an important source of family help.

In 1977 I started a three year study into short term care for mentally handicapped children. The work was financed by The King Edward's Hospital Fund For London and undertaken from the Thomas Coram Research Unit. Between 1977 and 1980 approximately fifty premises were visited, several months were spent living in hostels and hospitals, ninety families were informally interviewed and information was obtained on five hundred children receiving some form of short term residential care. I wanted to get beneath the basic idea that short term care is good because it gives parents a break from looking after a difficult, tiring child, so in the visits and interviews I tried to gather information on the following issues:

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- What the parents expected from short term care and whether they were really satisfied with what they were getting
- What the care staff thought they were doing for the families and children
- Whether the service was based merely on a rather vague notion of giving the parents relief by separating their children from them for short periods or whether it was built on clearly defined aims which had been thought out in a systematic manner and were related to good practices in child care
- What quality of care the children were receiving - their relationships with the care staff - their activities
- Whether they got homesick and how the staff and parents coped with this problem

SHORT TERM FOSTERING

The countrywide visits revealed a rapid growth in short term care schemes, some being organised by local authorities or area health authorities, others by voluntary organisations or parent groups. They varied in organisation and quality of care. The short term fostering schemes, pioneered by Somerset and Leeds social service departments in the mid-seventies and now available in at least fourteen other areas, provided the most interesting examples of neighbourhood care. The development of short term fostering is possible through Section 12 of the Health Services Public Health Act 1968 (now Section 21 and Schedule 8 of the National Health Services Act 1977) which not only enables local authorities to meet the costs but also means that this form of fostering is not subject to the same legislation as ordinary fostering under the Children's Acts so the handicapped children do not have to be received into the care of the local authority in order for their parents to receive this support.

Leeds was one of the areas visited repeatedly during the study. The foster parents there are known as 'placement families' in order to distinguish them from ordinary foster parents. The social services department recruited them by advertising on local radio, television and in newspapers, and before taking their first handicapped child they were interviewed and received some basic training i.e. visits to special schools and hospitals and careful introduction to the children's parents.

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Between 1976 and 1979 107 handicapped children in Leeds were placed with 31 placement families. The number of different familes supported by each placement family has varied from one to ten, but it is customary for only one child to be accepted at a time unless there is a special reason to take more, e.g. when there is more than one handicapped child in a family, a brother and sister may go away together. The majority of the families only make use of the scheme during the school holidays or for an occasional week or weekend every few months, but there are a few who make regular frequent use such as two weeks in every other month throughout the year.

The children who have so far used the Leeds family placement scheme are aged from two to nineteen years old and have a wide variety of mental handicaps including grave multiple disabilities and behaviour problems. The placement families, the majority are married couples with their own children, but six were on their own (widowed, unmarried or divorced). Although the majority had no previous experience of working with handicapped children they have shown an encouraging ability to adapt their homes and family life to meet the needs of their mentally handicapped visitors and have found the work very satisfying. One result of the scheme has been the development of supportive friendships between some of the natural and placement families. Current payment to the Leeds placement families is £57.70 per week (1980) and the handicapped children's parents do not lose any of their allowences whilst they are away. The overall advantage of short term fostering as against care given in hostels and hospitals is that it enables the children to remain in an ordinary family home environment.

The Leeds scheme is still expanding and seems unlikely to lessen although its organisation may change. All the foster schemes have slight differences regarding recruitment, training, the matching of families and the method of payment, because each authority develops its scheme autonomously and no overall method of organisation has yet been decided as best. However, as the value of short term fostering is now widely accepted, there may be a need for some organisational guidelines to be drawn up nationally, which would not only help new areas wishing to set up such schemes but might also safeguard standards of care.

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HOSTEL SCHEMES

Local authority hostels which provide short term care vary considerably with regard to their organisation and quality of care. Some are newly built specially for the purpose, others are old established hostels which have now started to offer a small number of short term places. Some are being criticised by parents because they have rules of admission and refuse to accept children who are totally dependent or show signs of behaviour problems. This "creaming off" of the most able mean that the least able and most difficult children have to receive short term care in mental handicap hospitals which may be a considerable distance away. When this happens, the parents and hospital staff begin to regard local authority mental handicap services with a certain cynicism.

If the local authority social services departments are to retain any credibility regarding commitment to the development of community care for all mentally handicapped children, it would seem very important for care staff to be well supported from senior management and have the aims of the service spelled out very clearly to them. A good example of the type of senior management needed in order to run a family support service was found in Reading where a twenty-bedded short term care hostel called Heath Croft opened in 1977. The managers and care staff at Heath Croft have always maintained that their aim is to provide care as needed to all families regardless of how severely handicapped or difficult their children may be, so the admissions are arranged as much as possible for the times best suited to the families' needs and no child is turned away solely because he is too handicapped. The policy has meant considerable pressure being put on the care staff, particularly during the school holidays; in one week in October 1979 thirty-four different children went through the hostel, three staying the whole week, the others between one and five nights. They were aged from four to seventeen and their handicaps included complete dependence and some behaviour problems. The cost to the local authority of accommodating a child at Heath Croft is £183 (1981), and since Spring 1980 the parents have been expected to contribute £7 a week towards this cost.

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Mr Lawrence Klein, Assistant Divisional Director of Social Services for the Reading Division of Berkshire Social Services Department has been directly responsible for Heath Croft since its opening and has demonstrated that if residential care staff are given consistent support from senior management in the form of regular weekly visits and counselling about their aims and problems, then it is possible for a hostel to provide a good service to all families who require help. Heath Croft, having twenty beds, is obviously far too big and it is probable that some of the children become very confused by the constant comings and goings of staff, parents and other children. Such a large 'home' is really not advisable. However, its philosophy of accepting all children and serving a local community, combined with the critical but supportive management policy developed by Mr Klein, might be profitably copied by other local authorities planning to set up short term care services. An ideal service would be based on the Reading philosophy of care and management but using ordinary local houses with not more than four or five children in each house. The idea of using ordinary housing for residential care is becoming more acceptable now (eg Skelmersdale, Lancashire, Barnados have used ordinary housing for the long term care of mentally handicapped children since the mid-seventies).

USING LOCAL PROVISION

The majority of mental handicap hospitals provide short term care, some setting aside a special ward for the purpose, others admitting two or three short term children into their long stay wards. The staff regard this service as a valuable function of the hospital and they encourage families to use it. However, most mental handicap hospitals are not only beset with problems caused by staff shortages, but they tend to be removed from the community they are supposed to serve, and are fundamentally inappropriate as a residential facility so to use them for short term care would seem ill-advised unless they have a separate, locally based children's unit which is small and well staffed.

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It has been the practice in some general hospitals for a small number of very severly handicapped children to be taken occasionally into the sick children's ward for short term care. This generally occurs if a family has a non-ambulant gravely multiply handicapped child under the regular care of a paediatrician who notices that the parents are getting stressed and suggests a 'social' or 'holiday' admission to one of his beds. Although his suggestion will be motivated by compassion for the family, the placement of the handicapped child in a general hospital for a 'holiday' is equally as undesirable as admission to a mental handicap hospital - the most obvious disadvantage in this care being that the child will go into a sick-ward environment and be surrounded by ill children. Admission to a general hospital has even been used for ambulant mentally handicapped children when nothing else has been available; one sick children's ward had more than twenty lively mentally handicapped children pass through during August, much to the consternation of the staff, who were nursing seriously ill children and not equipped to provide holiday activities for healthy demanding children who should have been placed in a far more appropriate residential setting.

EMERGING ISSUES

The final report of the study is being prepared for publication at the end of 1981 and will include further discussion on the above issues. Some preliminary findings and recommendations are as follows:-

One: Present short term care services are planned too much around the idea that mentally handicapped children are terrible burdens to their parents, so the best answer to the problem is to provide a residential service which will offer relief through separation. In their unquestioning support of this idea, many professionals seem to be under-estimating the love that parents feel for their handicapped children and not appreciating their reluctance to send them away from home.

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It was found that decisions to place children into a residential setting were being taken far too lightly, with little consideration being given to the possible effects on the children and very few explanations to the parents about what residential care actually means in terms of separation. Some parents were being persuaded to use short term care in hospitals or hostels becuase professionals thought they needed a 'break' - but they did not enjoy the break at all because they were left feeling guilty and anxious about their children. A typical example of what can happen is that of a single mother who was urged by a social worker and teacher to send her well-loved but difficult child away from home for a weekend so that she could have a rest. He was placed in a new purpose built short term care hostel many miles away and went their by school transport after school on Friday and came back to his mother after school on the following Monday afternoon. Having consented to his placement she received no help in coping with the emotional upset of the separation, and had no positive involvement whatever in her child's experience and did not meet the care staff or see where he went. Her only contact was the telephone call that she made to the hostel during the weekend to enquire if he was alright. The professionals sincerely believed that she was being helped by the service, but she actually spent a worried unhappy weekend feeling thoroughly guilty that she had let herself be persuaded to send her child away. In planning a short term care service it should be borne in mind that many parents do not necessarily want a residential service but would prefer a reliable 'sitter' in their own homes once a week, or a local day centre where they may with confidence leave their children to be looked after for a few hours after school, during weekends or in school holidays.

Two: Residential care staff are not always sure of their aims in giving a short term care service. They say 'we support families' or 'we give families a break', but when questioned about their claim to support families, they seem unable to link this to the daily care of the children and the support of the family as a whole: they are inclined to be very vague about such matters as how they might meet their children's play needs, how they cope with homesickness and how they maintain supportive relationships with parents before and during the period their children are receiving short term care and after they have gone home.

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Three: Parents prefer short term care services to be local rather than in homes, hostels and hospitals many miles away. A locally based service means they can be involved more easily in their children's care, visiting the unit, getting to know staff and occasionally making use of the premises for the day care whilst they go shopping or keep an appointment. One mother with two frail and dependent severely handicapped sons was reluctant to make use of residential care and needed considerable sympathetic explanations about what such a decision meant before she plucked up courage to first let one and then both boys spend a night away from home. She was able to accept the service because the unit was within walking distance of her home and she could take the children round there and put them to bed herself on the first few occasions that she used it. Although this mother badly needed help in caring for her sons, it is doubtful if she would ever have accepted short term care if the facility had been a long distance away. She wanted support that was local and familiar and enable her to share in her sons' experience of being away from home. Both her children have since died. An important aspect of the help she received is that she has not been left with distressing memories of sending her children to a strange and distant place in the final months of their lives.

Four: Planners, managers and care staff do not always appreciate the likely effects of short term residential care on the children. From observations it seemed that some were suffering homesickness, but this was not sufficiently recognised. In fact, there seemed to be a general agreement that mentally handicapped children were not likely to suffer when separated from their families; and parents were encouraged to collude in this idea, their worries about their children's homesickness being brushed aside by the professionals. In answer to the questions about homesickness, the officer in charge of one hostel said "of course homesickness is no problem with these children as they do not have the same emotional feelings as normal children". Such insensitive and unfounded theories were disturbingly common. It would seem a matter of grave concern that in trying to set up supportive services for parents we may be doing to mentally handicapped children the sort of insensitive things that we try not to do to ordinary children in case we cause emotional distress and lasting damage. All too often it was found that old-fashioned patterns of residential care prevailed for mentally handicapped children and they were not receiving the same reassuring considerations which are given to ordinary children who have to experience a separation; for example, some were receiving short term care in hostals and hospitals to which they had never been properly introduced; parents were being advised not to visit and were told to leave immediately

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after delivering them because "they'll settle as soon as you have gone'. Some where stripped of their own clothes and were discouraged from keeping their personal toys by them, many were delivered by school transport or social workers instead of by their parents even when they lived fairly near and could have easily come in with them and stayed a while.

Five: It seems that children aged under five are being admitted unnecessarily to short term care. Some parents said that they had misgivings about making use of a residential service for such young children, especially as they were not presenting any more problems at home than ordinary under-fives, but they used short term care because social workers, teachers, care staff and even other parents seemed to be putting pressure on them to do so. This phenomenon of parents being consciously or unconsciously pressurised into using the services seemed to occur most often when a hostel had just been opened or a ward up-graded and the admissions needed to be kept up in order to justify the enormous costs of building and upgrading.

Anyone planning short term care services might well bear in mind that the admission of the under fives to hostels and hospitals should only occur in the event of grave circumstances and when no other form of care can be found, such as staying with a relative or neighbour or having a 'sitter' at home. Criteria for admitting under fives to a residential service might be:

- if the handicapped child is at risk due to rejection or neglect at home and the parents need to have massive support in order to accept him and care for him properly
- if he has a chronic problem which is causing grave stress to the rest of the family, such as persistent crying, disturbed nights or severe feeding difficulties
- if he has a complicated condition which his parents need help in coping with and necessitates him receiving some very specialised medical or nursing care which cannot be given in the family home.

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The work of Honeylands, Exeter, in supporting families of handicapped under fives, where admission to the residential section is always combined with support to the family from the professionals based in Honeylands, would seem to be a suitable model to aim for with regard to the under fives. Or the model of service development from Balidon House, Yeovil, where parents of handicapped under fives are supported by day care services combined with occasional shared care with a 'foster care family' or in a voluntary society home for multiply handicapped children. The Honeylands and Balidon models of care are different, but both ensure that residential care is not arranged unless it is absolutely necessary and it is always in conjunction with very supportive day services.

Six: There is not always very good cooperation between the various professionals when children are using short term care. For example, it was found that physiotherapists, psychologists, speech therapists and teachers could have been more positively involved with care staff regarding the sharing of information on children's programmes of communication, movement and learning skills. It was difficult for the care staff in hostels or hospitals to help children unless they are kept fully informed by other professionals about what the children were doing in school and at home and given the appropriate instructions about how to follow out any programmes.

Special schools, in particular, might have played a more positive role. It was disturbing to note that some school staff were almost obstructive towards short term care services; for example, the teachers in one special school never bothered to make any contact with the staff of the hostel where many of the children regularly went, but they created dissent between the parents and carestaff by reporting to parents that their children had been sent to school from the hostel incorrectly dressed or badly placed in their wheelchairs. The very helpful role played by some schools emphasised the importance of teachers involement in the children's residential care experiences and showed they could act as positive links between family, short term care unit and school; for example, the staff of one special school worked closely with care staff and tried to ensure that the children were happy and supported during their stay; they would take groups of children on occasional mini bus trips to the hostel so they could play in the garden and become familiar with the environment and the staff, and they collaborated with parents and hostel staff in arranging that children who were particular friends at school might stay at the hostel at the same time so that their stay could be more fun for them.

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SOME BROAD CONCLUSIONS

The idea of short term residential care hasbecome popularly accepted without sufficient exploration of exactly what the service should be aiming for in terms of child care and family counselling. Whilst I accept that families may need occasional, even regular, help in looking after their handicapped children, I would also urge that more concern should be shown regarding decisions to take children into residential care, and the separation of the child and his parents should be managed in a far more sensitive manner. More attention should be paid to the children's individual needs and the effect that separation might have on them. There is a need to get away from the popular idea that all mentally handicapped children are burdens and that all problems will be eased if only there is some short term residential care available. Such a concept is unfounded. For most families the process of separation is a painful one.

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SOME GUIDELINES FOR PLANNERS OF SHORT TERM CARE SERVICES

1. Staff working in short term care services should constantly review their aims and ask themselves critical questions about the quality of care they are providing for the children. This might be done through regular staff meetings, seminars and in-service training.

2. The service should always be parent involved. ie with parents represented on the management of the hostel or hospital ward and fully involved in deciding the aims of the service.

3. The service should always be local.

4. The service should be varied so that families can have a choice and use the type which will suit the particular needs of their child at a particular age - this may be fostering in another family, care in a small local hostel or somebody coming into the family's own home for short periods. The needs of the child and his family will occasionally change and this should always be taken into account.

5. The service should be linked with the children's school and have the close cooperation of their teachers and other professionals.

6. Very careful thought should be given to the admission of children under five to a residential setting for short term care. It should only occur if absolutely necessary for the emotional or physical health of the child, his parents or sibs; and whenever possible, it should be given in another family or a very small home so as to avoid the strange environment and multiplicity of carers inherent in hospitals and large hostels.

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APPENDIX : FURTHER INFORMATION

Reference has been made in this Paper to the Leeds Family Placement Scheme, the philosophy of Heath Croft (Reading), and the work for the under fives at Honeylands (Exeter) and Balidon House (Yeovil). Anyone wishing to know more about these services may like to get in direct contact with people at the following addresses:

Mr Malcolm May, (Principal Adviser-Mental Health),
Leeds Social Services Department,
Merrion House,
Merrion Centre,
Leeds.

Mr Lawrence Klein, (Assistant Divisional Director),
Berkshire Social Services Department, (Reading Division),
7 Cheapside,
Reading, Berkshire.

Mrs June Jones, (Administrator),
Honeylands,
Heavitree,
Exeter, Devon.

Mrs Ailsa Way,
Balidon House,
126 West Coker Road,
Yeovil, Somerset.

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Listed below are several other places of particular interest which were found during the study. They are all different, and none of their initiators would suggest that they have the definitive answer to what ought to be happening regarding short term care services, but they are listed because they provide interesting examples of the ways in which some professionals and parents are seeking new and imaginative ways of creating good local services to meet the varying needs of children and parents. Any of these schemes could be successfully copied in other areas:

The Birmingham Multi-Handicapped Group: (Parent Relief Service):

This is a scheme which was started in Birmingham in Summer 1980 by a small group of parents of severely handicapped children. It helps by arranging for a Care Attendant to go into the home and look after the handicapped child for a few hours, at a time best suited to the family. The scheme is grant-aided and the Care Attendant receives a fee for the hours of care that are given.

Contact: Mrs Mary McCormack,
35 Larchmere Drive,
Hall Green,
Birmingham 28

Torrington House Hostel, Chesham, Bucks

A short term care hostel providing accommodation for ten children, open seven days a week, fifty weeks of the year. It was opened by the Parent-Teacher Association of Heritage House School, Chesham, through the purchase and conversion of a local farmhouse in 1976.

Contact: Mr David Haddock,
The Head Teacher,
Heritage House School,
Nalders Road,
Chesham, Bucks.

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Springfield House, Witney, Oxon.

Opened in 1978 by the Parent-Teacher Association of Springfield School after purchasing two semi-detached three bedroomed houses on an ordinary local estate and converting them into one house which can take a maximum of six short term care children at a time. It is owned and managed by the Parent-Teacher Association who employ a 'foster-family' (a married couple and their adult daughter) to live in the house and act as houseparents.

Contact: Mrs Ann Hunt,
Church Farm House,
Church Road,
North Leigh,
Oxon.

Rees Thomas School Hostel, Cambridge

This originally opened in the early 1960s as a local education authority hostel accommodating those pupils who had long distances to travel to school and needed to stay from Monday to Friday. Since Summer 1977, however, it has changed its function from being just a Monday to Friday boarding hostel to being a family support service, it has received joint financing from the local authority social services department and the local education authority, with some of the care staff being paid by the social services department and some by the local education authority. It can take twelve children.

Contact: Mr John Morton,
Head Teacher,
Rees Thomas School,
Hawkin Road,
Cambridge.

The Little House, Hendon, London NW4

A mobile home on a small site in Hendon, used as a family support centre and run by staff of St Joseph's Centre Pastoral Office for the Handicapped in the Diocese of Westminster. It offers day care and overnight care and since it opened in 1979 it has

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been able to help more than fifty handicapped people (including those who are physically handicapped and mentally handicapped, adults and children). It is an unusual form of family support because it does not consist of a large expensive building and it is being developed from the Diocese of Westminster instead of from the local authority or the area health authority.

Contact: Rev. David Wilson,
St Joseph's Centre,
Pastoral Office for the Handicapped
(Diocese of Westminster),
The Burroughs,
Hendon,
London NW4

More information about the study on which this paper is based and the 1981 programme of dissemination can be found by contacting:

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