



# **THEY KEEP GOING AWAY**

**A critical study of short-term  
residential care services for children  
who are mentally handicapped**

**MAUREEN OSWIN**

**King Edward's Hospital Fund for London**

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

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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.

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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

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## 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,

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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<sup>1</sup>, Platt report<sup>2</sup>, Freud<sup>3</sup>, Hall and Stacey<sup>4</sup>, La Fane<sup>5</sup>, Battye<sup>6</sup>). 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<sup>7</sup>).

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.

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

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*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 A 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.

## References

- 1 Robertson, James. *Young children in hospital*. Second edition. London, Tavistock, 1970.
- 2 Great Britain, Ministry of Health. *The welfare of children in hospital: report of the committee*. (Chairman, Sir Harry Platt.) London, HMSO, 1959.
- 3 Freud, Anna. *Infants without families and Reports on the Hampstead Nurseries, 1929-45*. London, Hogarth Press, 1974. International Psychoanalytical Library.
- 4 Hall, David and Stacey, Margaret, editors. *Beyond separation: further studies of children in hospital*. London, Routledge and Kegan Paul, 1979.
- 5 Fane, Pamela La. *It's a lovely day outside*. London, Gollancz, 1981.
- 6 Battye, L. *I had a little nut-tree*. London, Secker and Warburg, 1969.
- 7 Bowlby, J. *Maternal care and mental health*. Second edition. Geneva, World Health Organization, 1952. Monograph series no 2.





## I 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 (now 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;