KFC/80/307

KING EDWARD'S HOSPITAL FUND FOR LONDON

King's Fund Centre

STRESS AND THE CARING RELATIVE

CROSSROADS SCHEMES FOR MENTALLY HANDICAPPED PEOPLE

Report of a meeting held at the King's Fund Centre on 13 June 1980

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

The number of Crossroads schemes (1) in the U.K. and Northern Ireland has been growing steadily since the establishment of the first scheme in Rugby in 1974. There are now twenty three schemes in operation providing care attendants to relieve people providing care for a disabled person in the community. The Crossroads schemes are clearly aimed at the relief of stress in families caring for a physically handicapped person; but the third in a series of King's Fund Centre conferences (2) focussed on the applicability of these schemes to families caring for a mentally handicapped person.

The Chairman, Mr John Jones, Assistant Director of Social Services, London Borough of Newham, said that the aim of the day was an exchange of information between those with experience of care attendant schemes and those with experience of the needs of the mentally handicapped and their families. The first speaker, Mr Richard Ambury, Development Officer, Crossroads Care Attendant Scheme Trust, said that he had first become involved with a Crossroads scheme when he was Area Nurse (local authority liaison) with Essex AHA. These schemes operated in what Dr Frank Tait of the DHSS had described as the 'no man's land' between statutory and voluntary services for the handicapped, that was in fact 'everybody's field'.

There had been a dramatic shift of emphasis over the past decade, which was still being promoted by the DHSS, towards community care; but the extent to which resources and services had been switched out of institutions into the community, was very patchy. The extent of domiciliary nursing services or community therapy services, for example, varied considerably and there was no separate Whitley scale for community nurses for the mentally ill and mentally handicapped. There had been considerable development of social service provision for these groups including new social training centres some with special care units attached for severely multi-handicapped over sixteen years of age, but generally the emphasis on the family as the primary caring agent had developed without a consistent pattern of back-up and support. This was where Crossroads and other care attendant schemes came in.

The Trust deed which had been drawn up for the original Crossroads scheme was now being redrawn to establish the Association of Crossroads Care Attendant Schemes, but the objectives would remain the same - to identify the carer who was coping from day to day and who would benefit from a break on a planned or crisis basis. The stress faced by the carer had been discussed at length in the earlier conferences and included physical exhaustion and anxiety, financial and environmental problems, social pressures and isolation and a great fear of the future. Along with these stresses there was usually a great measure of pride and independence to 'go it alone', borne often out of desperation and a lack of any other alternative.

Each Crossroads scheme was run by a local voluntary committee, usually representative of statutory and voluntary interests, and concerned to assess local needs and to channel services to meet them. The scale of the problem varied greatly. Islington for example, was aimed at a population of 170,000 in about five square miles of Inner London, while Braintree covered a District population of 110,000 in 250 square

miles of largely rural Essex. The local co-ordinator and the care attendants were paid employees of the scheme. Care attendants moved in to do everything that would have been done by the carer during the period of relief. Help with the training of care attendants came from the community nursing and home help services, but the main emphasis was on the family doing the training as the experts in the care needs of the disabled person.

The number of hours of care available was dependent on the funding available to or raised by the local scheme, for example £10.000 p.a. (for 1981 scnemes a figure of £15,000 per annum would be required) would buy about 80 - 100 care hours per week spread as the co-ordinator thought best. This would help about twenty families and might avoid the need for admission to residential care and maintain the health of the carer. This was clearly cost effective when set against the cost of a bed in a hospital unit for the young disabled - currently about £200 per week. Mr Ambury urged participants to recognise the status of carers and to support a reconsideration of statutory and voluntary provision for the disabled to give more support to the carer. This was equally applicable to mental handicap where there was least community provision for the most handicapped and therefore a great need to bring relief into the home. A parents relief scheme had been set up in Birmingham (3) to do this and a number of care attendant schemes included multiple handicapped patients.

The need for regular support was reinforced by the second speaker, Miss Maureen Oswin, a Research Officer with the Thomas Coram Research Unit. Miss Oswin said that most families caring for a mentally handicapped person were only offered help when a crisis occurred and there was no time for a proper review of alternatives and temporary or permanent residential care was the only remedy offered them.

Carers often staggered on living a half life, without real hope, for years, and stress went unnoticed by the average social worker making a rare routine call. It was indeed hard for the social worker to understand the physical strain and exhaustion, the endless patience involved in caring for someone with a very limited capacity to respond, the broken nights and the added stress of increasing old age and anxiety about the future. Familes learnt to cope, often in quite bizarre ways, and developed routines that made life possible in their own situation. A great deal of love went into these routines, and families would only be prepared to accept help if it fell in with their ways and measured up to their standards.

Families caring for a mentally handicapped person valued their security and self respect and would not use bad services. Indeed the provision of poor and inappropriate services and the lack of services which met their real needs added greatly to the relatives stress. Miss Oswin illustrated this with reference to holiday residential relief schemes which families found so unsympathetic and unsatisfactory that they either cancelled their planned holiday, were unable to enjoy the break or came back and found it had so disturbed the handicapped person that all the good of the change was undone.

Services had to be provided which would cherish and respect the carer and their way of doing things and which would keep families together. Crossroads schemes were one way of doing this. They offered help at the time when it was needed, but this needed to be especially flexible in relation to mental handicap. For example, there were some mentally handicapped people providing as much physical care for very elderly parents - cooking, cleaning etc. as the elderly parents were providing a framework and support for them. Regular visits from a care attendant might maintain a household of this type, and help offered actually in the handicapped person's own home rather than in premises some miles distant helped to maintain the handicapped person's link with his adult training centre. Other families needed help so that more time might be spent with the brothers and sisters of a handicapped child.

Participants picked up the need for flexibility in the relief of stress in families with a mentally handicapped member, in discussion after this contribution. Particular concern was expressed about families who had kept a son or daughter at home for 40 - 50 years and were reluctant to bridge the gap to residential care when they had gone. The example was given of a hostel that offered trainees in this position the opportunity to have supper at the hostel between the training centre and Gateway Club one night a week, as a first contact. Only seven trainees had accepted this offer and the majority had never gone out in this way before.

A support scheme needed to do more than just relieve the carer, it needed to build up the independence of the handicapped person, to provide a link into the wider community and to break down the sense of isolation. To a great extent there were already statutory and voluntary bodies trying to do this in the field of mental handicap but too often their work was limited by existing policies and lack of money. The local authority hostel faced the problem of who pays for the trainee's tea? The voluntary body set up a short stay holiday relief hostel but everybody wanted a place in August. A funded care attendant scheme such as a Crossroads or a Leonard Cheshire Foundation scheme might make it possible to offer families the services they wanted rather than to make them feel guilty at not accepting the services that were offered.

Practical experience of the adaptation of care attendant schemes to the needs of the mentally handicapped was provided by four organisers. Ms Judith England of the Brent Care Attendant scheme said that she had had experience of two mothers caring for very severely mentally and physically handicapped sons, one in his thirties and one aged six. She had spent a great deal of time talking to them and involving a care attendant but neither had maintained use of the service. It appeared to be helpful to both women to know that practical help was available if needed, but that the longer they carried the burden of care, the more emotionally dependent and unable to relinquish it they became. So help needed to be offered while a child was still very young so that mother and child did not become settled in their isolation and dependence on each other.

Miss C Ringwald described the West Dorset Family Support Service (4) sponsored by the Cheshire Foundation. This was a very new service aimed at families with a handicapped child under sixteen, Fourteen families had been referred and twelve planned to use the service. Again it appeared important to families to know that help was available even if they might not use it. Thirteen care attendants were being employed in a very rural area and the families had the responsibility for training as they would a trusted friend or relative. In practice this meant becoming involved, perhaps learning sign language to permit communication. Families were charged fifty pence an hour for the service but assistance from social services might be available where the referral had come from the Social Services Department. The West Dorset Family Support Service would not refuse help to any family in need because of inability to pay.

Ms Moira Wilkinson, Co-ordinator, Newham Care Attendant scheme, said that this scheme had been in operation for just over a year, and that it had been decided to include families caring for a mentally handicapped person from the start. However, there had only been four such referrals out of a total of forty eight. One had not come in time to prevent the handicapped person being admitted to hospital care. In the other cases support had delayed the admission of elderly mentally handicapped twins, had provided regular cover for a young family when the mother had to go into hospital and in one case had not been taken up.

The Havant Care Attendant scheme (5) was then described by Mrs Jill Matthews, one of the care attendants, who had had 15 out of a total of 107 referrals to help a family with a mentally handicapped member. Only one of these had not made use of the scheme but the help was provided in a very flexible way. For example, one mother used the care attendant to accompany her on a social trip out each week, while her daughter cared for the handicapped person. The widowed mother had, through her care of her mentally handicapped son, become isolated, with no friends or social events. She felt incapable of going out unless accompanied by the attendant, who she looked upon as her only friend. The outing was used by the attendant as a counselling session to a great degree. This joint financed scheme also ran a playgroup for children whose parents were handicapped in any way, including for example parents who were unable to speak and whose children therefore needed help with language development. The aim was to fit in with a family's needs, whatever these were, and a lot of careful matching was needed between families and care attendants. The main qualities that were needed in a care attendant were patience, an ability to get on with all sorts of people and to accept their way of doing things, adaptability, a sense of humour and an ability to cope with the stress that was transferred to them.

In discussion, participants queried whether there was a place for male care attendants. Most schemes apparently had one or two who could be most useful in certain families; but generally it was felt that the pay offered was not attractive to men, and that as most carers were women they related better to and were more confident of women care attendants. Recruitment did not appear to be difficult and most schemes used advertisements in the local press.

A parent view was put by Mr K J Crowe, member of the Southend Society for Mentally Handicapped Children. Mr Crowe said that he welcomed the interest that Crossroads was now taking in the problem of mental handicap. Southend had had one of the first Crossroads schemes and the local Community Health Council had played a major role in getting it started. This reflected to some extent the way in which families were increasingly accepting the responsibility of home care of handicapped people. In the field of mental handicap the 'experts' no longer pressed institutional care as the only solution in the way they had 15 years ago; but services to support families in the community were still very patchy and varied from district to district.

It was vital for families that services should be improved and developed and particularly short term residential care and flexible support such as that provided by Crossroads. Many families had the same problems as those faced by families with a physically handicapped member - the need for constant attendance to physical needs and bodily functions with the additional problem of poor or non existent communication. An additional problem was that many mentally handicapped people were not static. The carer could not get on with things knowing that all was well. Instead the child needed constant attention and occupation which was very exhausting. It was like caring for a toddler for life.

The whole family was imprisoned with the handicapped child. Mentally handicapped people were sometimes perceived as exhibiting frightening and unpredictable behaviour which might be quite unacceptable to people who were not accustomed to it. All the members of the family to some extent shared in this loss of privacy, damage and embarrassment.

It was particularly difficult to introduce a care attendant into this sort of situation even though the help might be greatly needed. The family needed to be convinced that the care attendant could cope and a long introduction period might be needed. Mr Crowe said that the Southend society was now meeting needs by raising money to provide a special care unit attached to the local adult training centre. Parents were still not being offered what they really wanted, and there was a conflict and tension between what was on offer and what parents wanted and would accept, often after long years of struggle and disappointment.

Participants divided into groups for the afternoon session to consider further the needs of families with a mentally handicapped member and the way in which these needs could be met. The following points were made:

Needs

i) To live a life apart from the mentally handicapped member.

ii) To not feel isolated but to be in contact with other parents, perhaps through the voluntary society.

iii) To have proper support from the moment the diagnosis is first made and to know where help can be found.

iv) To receive continuous assessment and appropriate treatment, education and development for the handicapped person.

v) To have a life plan for their child going beyond the parents death.

Needs (cont'd.)

vi) To be able to prepare their children for independence and to let them go as other children go.

vii) To be able to make use of a wide range of practical help.

viii) To be treated as individuals and as a unique family.

ix) To consistency of support and guidance both in terms of personnel and of services; this applied particularly to the provision of personal social work services which had become increasingly discretionary and crisis orientated.

x) To have a point of contact, a link to others in a smiliar position, to services and to the outside world.

Ways in which they can be met

i) Support in the home from care attendant schemes to baby sitting schemes, including some well trained care attendants able to cope with very handicapped and disturbed people.

ii) Provision of a framework to fill gaps. A care attendant scheme cannot do this. Attendants may draw gaps to the attention of the co-ordinator, but attempting to plug too many is bound to direct the scheme from its main role.

iii) New initiatives like MENCAP, (6) a foundation sponsored by the National Association for Mentally Handicapped Adults and Children and supported locally to ensure that a mentally handicapped person will have ongoing guardianship, oversight and a home after his parents' death.

iv) All sorts of short term flexible residential and holiday care, day care, play groups and holiday schemes. Attention was drawn to a house in Bedfordshire which served as a base for professional and voluntary workers in the field of mental handicap and for a wide range of residential and day time activities.

v) Landlady and fostering or care family schemes as an alternative to residential care.

vi) Schemes to foster independence, such as school journeys, and to bridge the gap into the world of adulthood and work, e.g. Pathway schemes. (7)

vii) The establishment of community mental handicap teams to bring services together and to ensure access and continuity. Sometimes this was linked to a mental handicap register and the purpose of this had to be understood if families were to be willing to accept registration. Generally it was valuable to the identification of needs for service planning purposes, and to the assessment and follow up of individuals.

Finally the discussion groups considered what strategies would need to be employed to start a care attendant scheme in a new area. The following points were made:

i) Identification of need - drawing on national or local surveys and information.

ii) Changing of local attitudes - particularly getting health, social services and education to talk to each other to enter the 'no man's land' and to plan for flexibility, choice and above all, quality of life.

iii) Provision of funds - voluntary local fund raising, national organisations moving into this area, joint finance monies, grants from statutory bodies.

iv) Arousal of public interest - press publicity, advertisements, local public meetings, films and information from national organisations in the field.

v) Willingness to start small - and to expand when the need has been demonstrated and the organisation tested.

vi) Parent and relative pressure - these are the real experts and the people who have most to gain.

vii) Establishment of steering committee of dedicated people and appointment of a local full time organiser.

Participants recounted a variety of ways in which these strategies had led to the implementation of schemes with statutory or voluntary funding and stressed constantly how relatively modest expenditure (£20,000 - £30,000) could lead to immeasurable improvement in the quality of life and to savings on the provision of alternative more expensive services in a crisis situation. Care attendant services should certainly be part of the range of choice open to families with a mentally handicapped member.

REFERENCES

1. Crossroads Care Attendant Schemes.
Further information and publications listed below can be obtained from the Director at 94a Coton Road, Rugby, Warwickshire CV21 4LN.

(a) Handout leaflets on objectives and structure of the Trust and where schemes are situated.

(b) Booklet "Crossroads Care Attendant Schemes". This covers the need for such schemes and how to go about setting up a scheme.

(c) Crossroads National Statistics 1979/80
16 Crossroads Schemes were operational during the year April 1979 March 1980 and statistics were collated by the national organisation. These will be of interest to planners and development officers working in the community or for groups wishing to establish their own Crossroads Schemes.

2. Stress and the Caring Relative - Crossroads Care Attendant Schemes.
A report of two meetings held on 19 March and 7 May 1980 is available from King's Fund Centre, 126 Albert Street. Please quote KFC/80/15.

3. The Birmingham Multi-handicap Group Parent Relief Service.
Further information can be obtained from Mary McCormack, 35 Larchmere Drive, Hall Green, Birmingham 28.

4. West Dorset Family Support Service.
Further information regarding the scheme may be obtained from Miss C Ringwald, Organiser, c/o Dorset Community Council, 57, High West Street, Dorchester, Dorset.

5. Havant Care Attendant Scheme.
Further information regarding this scheme may be obtained from The Co-ordinator, Havant and S.E. Hants Care Attendant Scheme, Havant. Council of Community Service, Crosby House, 13 South Street, Havant PO9 1BU.

6. MENCAP - National Society for Mentally Handicapped Children and Adults. Further information may be obtained from 117 Golden Lane, London, EC1Y ORT.

7. Pathway Schemes.
Further information may be obtained from Mrs Valerie Cooper. Senior Pathway Officer, Pathway Employment Scheme, 169a City Road, Cardiff, South Glamorgan CF2 3JB.

The Long Term Care Team would like to express their thanks to the Crossroads Care Attendant Trust for their help in setting up the series of study days on Stress and the Caring Relative. The days served to identify other schemes that are being developed along lines similar to the Crossroads pattern and helped in a wider exchange of ideas and experiences.

Readers may also like to know that a survey report on The Experience of caring for elderly and handicapped dependents has just been published by The Equal Opportunities Commission. This is available from the Commission at Overseas House, Quay Street, Manchester 13 3HN.