KING EDWARD'S HOSPITAL FUND FOR LONDON
King's Fund Centre

EEC/DOE/CROSSROADS AND SUPPORT CARE PROJECT

Report of a meeting held at the King's Fund Centre on 15th October, 1980

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

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The fourth in a series of conferences held at the King's Fund Centre during 1980 on aspects of the work of the Crossroads Care Attendant Schemes, looked at the European Economic Community/Department of Environment/Crossroads Housing and Supporting Care Project. The conference was, like the others in the series, chaired by Dr. Frank Tait, Department of Health and Social Security, and attended by representatives of Crossroads schemes, health and social services and voluntary bodies in many parts of the country.

The establishment of the project

Dr. Tait, and Selwyn Goldsmith, Adviser in the DOE on housing services for disabled people, described how the project had come into being. Mr Goldsmith took participants back to the passage of the Chronically Sick and Disabled Persons Act (1) which required local authorities to pay attention to the housing needs of the disabled. He had joined the DOE to assist in the development of guidelines for local authority architects on wheelchair and mobility housing. It was recognised that housing on its own was not enough; disabled people required a variety of appropriate supportive services to enable them to live independently in the community.

The EEC had also been interested in the development of housing standards for the disabled and the UK was able to obtain funds for a linked research project on the use of housing adaptations and supportive services to enable disabled people to live independently in the community. Five local authorities were chosen to take part in the project: Islington, Braintree in association with Essex County Council, Daventry in association with Northamptonshire County Council, North Tyneside, and Dundee in association with the Tayside Region. A contract was agreed in 1977 between the EEC and DOE, and between the DOE and Crossroads. The DHSS helped with funding for the care support services of the project.

The growth of Crossroads

Pat Osborne, Director, Crossroads Care Attendant Scheme, then described the development of the first Crossroads scheme from very small beginnings in Rugby. Initially she had developed the scheme on a spare-time basis in addition to her job as a District Nurse to support the families of spinal injury patients and to prevent them having to return to the Oswestry Spinal Injuries Unit in the event of family breakdown. The major initial funding of £10,000 had come from Associated Television.

(1) The Chronically Sick and Disabled Persons Act 1970 available from HMSO

This Crossroads scheme had been conscious from the start that the real primary care team for a disabled person was the family and that the thing which forced people back into residential care was not difficulties in the provision of statutory services, but the collapse of the family support in face of problems of housing, finance, stress and exhaustion. They had begun by asking what help relatives needed, and found that this was probably a small amount but at set times dictated by the family, not by the nurse or care attendant.

Families needed to be confident in the reliability of the service and therefore it needed to be kept small with one co-ordinator to whom both families and staff could relate.

Even at this stage the Rugby group had recognised that the scheme needed to be specifically orientated and nationally based. The scope was widened from spinal injury to cover physically disabled people of all ages but not to include all groups requiring care at home, such as the terminally ill or the elderly mentally frail. The question of continued finance and expansion was solved in 1976 when the DHSS stepped in to fund the Rugby scheme for a further year as a pilot for expansion, and then asked Crossroads to establish five further schemes as part of the EEC/DOE research project. This had linked in well with Pat Osborne's own long standing concern with the housing problems of disabled people, and the realisation that in terms of both housing and support, the standard of care for a disabled person was very closely related to where the person lived. Crossroads stood for a national pattern and standard that could be adopted anywhere.

The objectives of research

Anna Bristow, Research Officer, Crossroads Care Attendant Scheme Trust, pointed out that there was general recognition of the need for a great variety of provision for disabled people including specially designed housing, mobility housing, home adaptations, community care and short and long term residential care. What was missing was some indication of the proportions in which these alternatives were needed. The research project had been based on a purely investigative approach but had been designed to give some answers to these questions on the balance of housing and care needs and the size of the problem in a local area.

The actual objective of the project had been described as "To assess the housing needs of disabled people, especially those needing supportive care services, and to evaluate how these needs can effectively be met by the provision of suitable housing, whether this be specially designed or adapted, in conjunction with appropriate domiciliary care services".

The research plan for each of the five participating areas had initially been:

i) to start a Crossroads care attendant scheme

ii) to make an assessment of the housing needs of families receiving Crossroads care

iii) to do any necessary adaptations to their homes using EEC money

iv) to re-evaluate after 12 months to see what differences the care and housing adaptations had made to the family's situation

v) to assess the local authority's adaptation procedure and housing provision for the disabled

vi) to assess the interpretation of the DOE wheelchair and mobility housing guidelines and their use and value locally

vii) to monitor the new care attendant schemes, and

viii) to establish further local projects as necessary and appropriate

It had not proved possible to stick to the research plan agreed in October 1977 because it had taken between 6 - 12 months to get the new care attendant schemes into operation, while the EEC money for adaptations had to be substantially expended by November 1978. Families, who it was thought were likely to participate in the Crossroads scheme, when established, had had to be identified for adaptations but in the event the overlap had proved to be limited. The research had then been based on three sources:

i) interviews with 140 families to assess the extent to which the existing housing provision met the needs of the disabled person and the family

ii) interviews with 62 families participating in care attendant schemes and postal survey information from a further 172 families

iii) information on a further 785 families from co-ordinators of Crossroads schemes outside the chosen areas, and

iv) postal survey information from 433 families on the disabled persons' registers in the chosen areas on their housing need.

Housing needs - the effectiveness of provision

The five local authority areas studied had proved to be very different in their provision of housing for disabled people and this diversity had helped the project to mirror the position nationally. Only one authority had provided a considerable amount of purpose built housing, two had relied on adaptations, one had a stock of housing built before the publication of the DOE guidelines and one authority had an extensive programme of modernisation and adaptation of vacant ground floor properties for wheelchair users.

The DOE housing standards for mobility and wheelchair housing proved very confusing to the layman but basically mobility housing was built to Parker Morris space standards but with wheelchair access to the property and a number of the principal rooms, but not including the bathroom. Wheelchair housing provides more generous space standards and wheelchair access to all rooms, but even this did not always provide enough space for the disabled person, his carer and equipment - especially if the use of the allowed space was not well thought through. The small additional space allowances could also make wheelchair housing hard to fit into a larger standard housing scheme.

The postal survey to look at the perceived housing needs of registered disabled people had shown that between 25 - 30% wanted to move to specially designed housing and considered that they had problems in their present accommodation which posed additional strain on the carer. Between 50 - 60% had problems in getting up stairs or in getting into and out of their bed, bath etc. which imposed physical strain on the carer. Generally those people who wished to move exhibited a potential for greater independence and attributed their current problems to their housing position; while those who did not want to move attributed their problems to their illness or physical condition and considered that the problems would exist wherever they lived.

The desire to move also related, not surprisingly, to the disabled person's economic position in the family. Where the disabled person was a child or elderly parent or relative, the income of the family was less affected and the disabled person was not seen as requiring access to the whole house. In the 25-54 age group great stress was laid on the need for access to the whole house and where the disabled person was in late middle age, perhaps with a progressive illness, there was a willingness to move to reduce responsibilities and strain on the carer. In the over 75 age group only those living alone wanted to move, and in most cases sheltered housing for the elderly would have met their needs. Many families did not want to move from the neighbourhood where they were living but between 34 - 37% of those who wished to move were also willing to move to another neighbourhood for more appropriate housing.

The survey of the housing needs of families receiving support from Crossroads Care Attendant Schemes shows up five groups:

i) a high proportion were so disabled that alterations could make little difference to their lives although they might help the carer

ii) a number who were severely disabled could become more independent with more space and provision for electric and electronic aids to enable them to live a fuller life, but would still need a great deal of help with personal care

iii) some could be completely independent in better housing, for example the strong paraplegic able to use the strength in his arms to undertake personal tasks

iv) families where adaptations could provide a great relief of physical strain to the carer, for example the provision of a lift

v) situations where the provision of better kitchen or bathroom facilities could reduce the need for help from statutory services like meals on wheels or bath attendants

Overall, 16% of the disabled respondents thought that they could be more independent in better housing and 34% of their carers thought that their role could be made easier if their housing were different.

Housing Adaptations

A total of 24 adaptations had been undertaken using EEC money. The work had been carried out using the participating local authority's normal procedures. In four cases the work was organised through occupational therapists and in one case through an adaptation officer - a valuable co-ordinating post provided there was someone else to know and cover the work when the officer was on leave. Delays had crept in at several stages of the work and fell into three categories:

i) delays arising out of the organisation and procedures of the statutory services - including the priority given to the work by architects, the other pressures on occupational therapists, financial and committee arrangements and communication between the departments concerned, especially social services and housing which were often run by different tiers of local government

ii) delays arising from the situation of the disabled person or family including a sudden deterioration in health, a change in the stability or composition of the family and conflict within the family when the needs of the disabled person in terms of space, etc., ran counter to the needs of other members

iii) delays due to practical problems, such as design difficulties or lack of space in the house, bad weather, strikes and the standard of workmanship. A long delay in actually completing the work, once started, added greatly to the existing strains on the family.

Anna Bristow said that a number of recommendations had clearly emerged:

i) the need for greater delegated financial powers to speed up decisions outside committees through the chairman of the committee or officers

ii) the need for formal and regular channels of communication between departments to identify and deal with delays

iii) the importance of the commitment of senior officers to the policy and the value of having a senior occupational therapist in a management position

iv) the provision of clerical support for occupational therapists or the designation of an officer to administer adaptations work.

The research project had included an assessment of the effectiveness of the adaptation works undertaken which had generally proved to achieve their objective where the family situation had remained stable, the space had been adequate and the work not skimped. The objectives had been only partially achieved or proved unsuccessful where the adaptation had been a compromise for financial or structural reasons. Adaptations can often only solve one aspect of a family's difficulties and, of the 24 families who had adaptations, in 5 cases a move to purpose built housing was still felt to be a better alternative and in 11 cases further work was required or problems remained. Further considerations include the high cost of good, well insulated extensions and the social isolation they can impose on the disabled person; the space requirements for a vertical lift and the inconvenience created by a stair lift in a confined space, the difficulties involved in using shower trays that have to be stepped into when a sloping floored shower, which would probably be more expensive, would be of much greater value in the long term.

Purpose built housing

It was felt that many authorities and housing committee members, may not appreciate the limitations of the specially built housing which had been provided. Thirty mobility and two wheelchair units sounded like good provision, but this was really only two homes for the people who could not be otherwise accommodated. The survey had shown that mobility housing studied was of very restricted value even for disabled people using a walking frame. It was suitable for elderly people but not for those leading an active family life. Similarly there was very little demand for one bedroom housing. Space was needed for a separate room for the carer, even where this was the spouse, or for a hobbies, workshop or office room for a disabled person confined to his home.

There was a particular need for more space in kitchens and bathrooms and for more attention to external aspects and details such as the slope of ramps, access to the dustbins, the design and positioning of windows etc.

Recommendations on housing

Anna Bristow concluded this session by saying that while she recognised that the Housing Departments which had been formed in 1974, often from a number of departments with different procedures and approaches, had many organisational problems to deal with it did appear that in some cases the housing needs of disabled people received a low priority. The Crossroads survey had indicated the need for action in the following areas:

i) A co-ordinated approach by housing, social services, architects and health departments to meeting and processing the housing needs of disabled people.

ii) The importance of taking the housing needs of all members of the disabled person's family into account.

iii) Better information to the public and to the staff who came into contact with the public on the authority's policy and provision in relation to housing for disabled people - the authorities which had produced a clear explanatory leaflet on the subject did not appear to have been inundated with inappropriate requests as a result.

iv) The maintenance of a separate housing list for people with special housing needs.

v) The identification of housing which has been adapted for use by a disabled person so that this can be reallocated to someone who can make use of it.

vi) The value of small infill sites to do small schemes with 1 or 2 homes for disabled people in an established community - a large number of small schemes meant that a disabled person was less likely to have to move away from his own neighbourhood to obtain suitable housing. It was also easier to allocate a small number of properties when they were built.

vii) The identification of disabled people to go into new housing some 3 - 4 months before completion of the scheme so that there was time to plan the move and to involve the occupational therapist in the final details of adaptations and in continuing support to the whole family. It was often hard to find takers for a new house at one week's notice and this could then be interpreted as a lack of need for specially designed housing.

viii) The need to build homes in a whole range of sizes. Two bedrooms was the real minimum but many families needed at least three.

Questions followed. Anna Bristow confirmed that most families wanted bungalows rather than flats where there was space to provide them. The extensions which were proving unsuitable for winter use had all been built some years ago and there was nothing in building regulations about heating requirements. Participants pointed out that nothing had been said about provision by housing associations or private developers for disabled people. Anna Bristow said that she had not had time within the project to look at housing associations but the adaptations work had applied to people in all types of housing, including private housing, although the Council's arrangements for charging for work varied. Selwyn Goldsmith pointed out that local authorities also had discretionary powers to pay up to 90% in housing action areas.

The problem appeared to be that there was a great variation in the use and interpretation of improvement grant procedures. The Council might require a great deal of additional work not covered by the grant to bring the whole property up to standard and the costs to the family would then be prohibitive. Local authorities were able to reclaim up to 90% of the cost of building new wheelchair housing in line with DOE guidelines but no comparable central standards or funding were available to private developers, who were generally unwilling to run the risk of building very specialist properties which might not sell. Many families were so financially handicapped by the disability of an adult member that they could not go into the private market. A questioner wondered whether planning powers could be used to require private developers to build homes at least to mobility standards and another suggested that local authorities should underwrite the building of private wheelchair housing with a guarantee that they would purchase the property for renting if it could not be sold.

The establishment and maintenance of Crossroads Schemes

Pat Osborne opened the afternoon session, which was chaired by Mrs E. Groves, DHSS, with further information on the development of Crossroads schemes since the start of the EEC project. Other types of care attendant schemes had grown up over the same period but Crossroads was unique in its focus on 'Care for the Carer' and on the physically disabled. They believed that domicilliary care was not the domain of any one professional group or of the family, but of all these elements working together to solve problems; and all were represented on local management committees, including disabled people and their families. Crossroads had developed into a national network and as national co-ordinator, she did not attempt to dictate but rather to provide an opportunity for local schemes to learn from each other and to support each other. Some of the problems encountered were common to all; others might be unique to one area for geographical or financial reasons but nationally they were there to help solve problems. Also to provide a great deal of practical help with matters such as time sheets, job descriptions and contracts which helped to get a new scheme off the ground.

The five EEC/DHSS funded Crossroads schemes had started from initiative at the top and contacts had had to move down to the grass roots. More usually the initiative for new schemes started at the grass roots and then spread outwards and upwards in the search for financial backing. The Steering Committee might have to work together for several years before funding was assured and this made a very sound basis from which to start work. The local co-ordinator was appointed first and then had to get to know local organisations and personalities before going on to recruit care assistants and visit families. The national co-ordinator played a role in the recruitment of local co-ordinators and in continuing support and problem solving.

The five schemes had now grown to 25. The amount of voluntary effort and commitment which had gone into this development was humbling and had made the Crossroads approach nationally known. There was still a long way to go, but Crossroads would continue to contribute to the status of the whole family of a disabled person.

Finding the facts

Judy Brenig-Jones, Research Assistant, then described the collection of data and interview procedure for the project. Interviews had been planned with 42 families in four of the participating areas 6 - 8 weeks after they became part of a Crossroads scheme, to be followed up by a second interview 12 months later to assess changes in their position. The first interviews had taken between 2½ and 3½ hours to conduct and had covered all aspects of the person's condition, disability and abilities, needs etc., the stress and strain on the carer, the help and support available to the family, their thoughts and feelings about quality of their life and housing situation, ways in which this could be modified and the effect of the Crossroads scheme. When the time came to conduct the second interviews a year later, 7 participants had died, 4 had greatly deteriorated and it did not prove possible to return to one area, so only 22 second interviews were possible.

As a second approach to the study, Crossroads co-ordinators were asked to keep a detailed record of all referrals over a two year period: a total of 785 referrals had been examined. This had been followed up with a two part postal questionnaire, with one part for completion by the disabled person and one for the carer. These questionnaires had been sent out in 1979 to 70% of the families in 14 Crossroads schemes. A 71% response rate had produced a total of 172 replies. The research team had also visited all co-ordinators to obtain information on the schemes and its organisation, funding, source of referrals, liaison pattern and future plans. This had shown how far the differences between schemes were affected by financial objectives, management arrangements and geography.

Using the Facts

Anna Bristow said that the information obtained from the whole project would be used to produce eight separate reports: one for each of the five participating areas concentrating mainly on housing, one on adaptations, one on Crossroads schemes and one drawing all aspects of the project together. All the reports except the one covering Crossroads schemes, would have to be approved by a Minister in the DOE and might take some time to appear.

The Crossroads report would cover aspects such as the development of schemes and the variety of local initiatives and funding. The funds available would be related to total population and total mileage covered in the various areas. The range per head of population extended from 9p - 23p in schemes covering between 130-250 square miles, 5p - 6p in schemes covering 50-78 square miles and 5p - 6p in schemes covering 5-25 square miles. Nine schemes considered that they were seriously restricted by insufficient finance.

On staff, the report would cover the background and training needs of co-ordinators, their average hours of work (between 20-40 hours with 30 the average and optimum) and the selection of care attendants. Of 120 care attendants only 7 were male but this was related to the nature of the work. Most co-ordinators thought it was useful to have one male care attendant. Other aspects were the growth and promotion of individual schemes, the dilemma of wishing to discover need but of not being able to finance further help and the source and rate of referrals. Taking the 14 schemes together, 40% of referrals came via the health service, 40% from social services and 20% from voluntary or community sources. Other aspects covered included the hours of care provided, the turnover in families receiving care, relationships with the national office, and the back-up, support and expertise that co-ordinators could call on. A majority said that they would look to the national office for advice but some found their local committee supportive.

Some schemes had to supplement their financial resources by up to one third with voluntary fund raising. Co-ordinators varied in their willingness to get involved in this. Some were quite opposed to fund raising. Eight care attendants seemed to be about the optimum number to be managed by one co-ordinator, and beyond this it was probably wiser to consider the alternative of a new scheme. On the possibility of statutory provision of care attendants, co-ordinators feared that this might cause schemes to lose their flexible and personal nature and the fact that Crossroads schemes are orientated around the needs of the family rather than what the scheme can offer. One of the EEC schemes was, however, to be handed over to the social services department and it remained to be seen whether the larger organisation would accept an approach based on time needed rather than tasks completed.

The second section of the report would deal with the disabled person and carers, and the key factors in accepting referrals for Crossroads schemes. This included elements such as the health of the carer, other commitments and statutory and voluntary support.

When Crossroads help was not provided it was usually because the carer's position was not judged to be sufficiently stressful, the need was felt to be for some other service, the family did not meet the criteria or lived outside the boundary of the scheme. The information on carers would include age, relationship to disabled person, health status and stresses and strains. 58% of respondents described health problems, either attributable to or aggravated by the caring role.

Crossroads schemes offered a range of support including a regular break, regular care with specific tasks, occasional breaks, overnight care and emergency care. The largest group of disabled participants had neurological disorders, particularly multiple sclerosis. The information would cover the timing, frequency and length of visits. Different schemes had different policies. Some helped a small number of families intensively, while others helped more families with less intensive but regular help. Generally, the more the help provided, the nearer the carer was judged to be to breakdown, and in need of emotional support. The benefits of Crossroads identified by carers included freedom and peace of mind, particularly for caring wives and daughters, and reduction of physical strain and continuation of employment, particularly for caring husbands.

Further sections of this report would deal with changes identified in follow up interviews, housing aspects and the work of care attendants. One interesting aspect was the involvement of care attendants in rehabilitation activities such as cooking, shopping and walking. There appeared to be scope for this to be linked to more professional support from occupational therapists and physiotherapists working in the community.

Concluding discussion

The conference concluded with a panel discussion involving all the day's speakers, chaired by Dr Tait. Asked about the role of Crossroads in the provision of counselling to families with a disabled member, Mrs Osborne said that this tended to be shared between the local co-ordinator who visited all families regularly and the care attendants who by their more frequent involvement, were able to provide some emotional support, and indeed often to become 'one of the family'. Problems were often brought back to the co-ordinator who needed to be very aware of situations when professional help was needed and to facilitate or encourage this referral. The induction programme for co-ordinators and care attendants had to include visits with appropriate professionals and voluntary organisations to see their contribution and roles. Care attendants had to remember that their job was only to replace the relatives. Co-ordinators often became a key person in linking families to health and social services because of their expertise and local knowledge.

Discussion then turned to the financing of new schemes. The Cheshire Foundation had a policy of starting schemes using voluntary monies and charges and contributions from those receiving help, so that they could demonstrate the need for the service to statutory bodies and make a case for funding. Pat Osborne said that Crossroads had exactly the opposite approach and did not start a scheme until funding was assured, however long that took. Local committees sponsoring the development of new schemes usually contained representatives of the statutory authorities in the area covered and this ensured their commitment to obtain funding from the start. Crossroads had a policy of not charging for care which families needed, although it was open to families to make a contribution either as a gift or a regular voluntary subscription. In the Rugby scheme voluntary subscriptions were paid by some families at the rate of 25p per visit and £1.00 for a night; but even this had only raised £900 towards the total cost of the scheme. A realistic charge would be beyond the means of most families who needed help, and most did not look on the scheme as 'charity' because they knew help was only provided because of their very real need for it. On the question of getting assistance from joint finance monies, the panel felt that this was a matter of local knowledge as policies and attitudes varied so much from area to area. There was general agreement, however, that voluntary schemes such as Crossroads were cost-effective and efficient; and to the extent that they saved family breakdown, avoided even heavier charges falling on the rate and tax payer.

On the size of schemes, the panel felt that this was very much a decision for local committees and co-ordinators. Some Boroughs and some committees might be able to support more than one scheme and some co-ordinators were working with up to 15 care attendants. Generally people felt that if a scheme got too big and involved too many families, it was not personal enough. It had to be kept manageable and individual like the size of a hospital ward. One questioner asked whether Crossroads help could be maintained if the carer died or for some other reason ceased to be there to care. Co-ordinators said that it was usually not possible because the disabled people involved usually needed too much help to manage at home without a resident carer, and Crossroads could not replace the carer.

Finally, discussion turned to housing and the difficulty of assessing the effect of better housing as a variable on its own, because so many other elements in the life of the disabled person and the carer had usually changed over the same period. Participants at the meeting knew of a number of cases where families had been very surprised at how little help a disabled person required when his home was successfully adapted or improved. However, much depended on the personality and attitude of the disabled person. Housing and care needs were, however, closely related and disabled people had found that they could manage with up to 50% less help than they had thought when they were in the right house. This led on to the concluding thought of the conference - housing and care provision for disabled people needed to be much more closely related by planners and service departments, and to take more account of the nature of the disability, the personality of the disabled person and the needs of his whole family.

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