KING EDWARD'S HOSPITAL FUND FOR LONDON

King's Fund Centre

OPTIONS FOR CARING FOR YOUNGER PHYSICALLY DISABLED PEOPLE

A Report of a Conference held at the King's Fund Centre on 21 June 1979

King's Fund Centre
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INTRODUCTION

The problems of identifying the client group usually described as 'the younger physically disabled' and of providing alternative and appropriate forms of accommodation and care services for them, were discussed at a conference held at the King's Fund Centre on the 21 June 1979. Following a welcome to the Centre from Mr David Hands, assistant director, and an introduction to the programme from the Chairman, Mr Philip Bolshaw, Chairman, Hertfordshire County Council Social Services Committee, participants heard eight presentations of different approaches to these problems.

DEFINING THE GROUP

Dr Frank Tait, DHSS, pointed out the need, first and foremost, to recognise that each disabled person was an individual with a unique personality, and particular relationships with his family, the community and the society of which that community was a part. The designation 'younger physically disabled' was little more than a convenient administrative label for a very disparate group, and it gave no indication of individual need. Furthermore it had to be recognised that in assessing needs factors such as individual temperament, the emotional and physical resources of the family, and the geographical location and level of facilities were as important as purely medical considerations. The concept of an individual profile of need along many dimensions, formulated by the Warnock Committee[1] in relation to education, was equally appropriate to decisions relating to the care of disabled adults.

'Younger physically disabled' describes those between the ages of 16 to 65 years but the group is not so young as is often thought. The OPCS Survey The Handicapped and Impaired in Great Britain (Amelia Harris)[2] showed that the mean age of the group is 50.8 years and more than half are aged 55 plus. Using activities of daily living as criteria Harris described those who had difficulty with several items as being severely affected and those who required assistance with activities that have to be performed more than once a day as being very severely affected. Adapting tables constructed by Dr Philip Wood from the Harris data it could be expected that in a total population of 250,000 (say a health district) there would be some 775 individuals who would be either severely or very severely affected. The majority of these, over 330 persons, would have conditions such as arthritis, strokes, parkinsonism etc which tend to occur at the upper end of the age spectrum, and only 66 individuals would have conditions which had been present since infancy and youth; a further 60 would have multiple sclerosis. However if we consider only those who are very severely affected the total group would now number only 200 and the younger ages become more prominent. Although some 70 individuals would have arthritis, strokes etc some 36 would have conditions which had been present from infancy and youth and a further 30 would have multiple sclerosis, together making a third of the total.

The responsibility for meeting the physical, emotional, employment, social and health care needs of disabled people falls on the disabled person himself as well as on a wide range of statutory and voluntary services.

This means that joint planning must not be restricted to an exercise between health authorities and social services departments; it must include education, housing, voluntary bodies and discussion with disabled people themselves. What is often called the 'no man's land' between health and social services responsibility is in reality an area of inter-dependent and share responsibility and one in which the whole community has a part to play.

COMMUNITY HEALTH COUNCIL INVOLVEMENT

The involvement of a Community Health Council in solving a local problem was described by Mrs J M Perry, Vice Chairman, Portsmouth and South East Hampshire Community Health Council. Council visitors had met two young post polio patients who had spent many years isolated in their own hospital ward, at a time when plans were being made to move them into the wing of an infectious diseases ward. This had triggered off an investigation into the numbers of other younger physically disabled patients in hospital wards in the District and an assessment of their needs and how these might be met.

The CHC study group had found a total of about 40 young patients in geriatric wards, had visited a variety of hospital units, hostels and homes for the disabled, had spoken to staff, patients and residents and to some of the disabled people in District hospitals. The Group had identified a need for support to enable young disabled people to live in their own homes backed up by periods of short term residential care to relieve their families. They had also recognised a separate need for longer term hospital or residential care for patients without family support, or in need of active rehabilitation or terminal care. The options had to be flexible and varied to suit the needs of people with very different personalities and circumstances, so as to provide an environment that would be acceptable for what might be the major part of a person's life.

As a result of the CHC initiative a wide range of statutory and voluntary bodies had come together to meet the residential and support service needs identified. Action included improved chiropody and dental services for the disabled, a two year pilot scheme for care attendants, sponsored jointly by the health authority and social services, and run by voluntary bodies using joint finance monies and further consideration of the most appropriate type of hospital unit. The whole exercise clearly demonstrated the role of a CHC in uncovering gaps in local services, in investigating proper provision and acting as a catalyst for new schemes like the care attendants, in monitoring rather than managing the operation of such schemes and in making the services known to potential clients within the health district.

HOUSING

A word of caution on options in housing was sounded by Selwyn Goldsmith of the Housing Development Directorate, Department of Environment. There were only two choices - staying in or opting out, running one's own life in the community or arranging for an agency to manage it on one's own behalf. There was however an increasing range of solutions which had emerged over the last ten years in response to developments in Europe.

Mr Goldsmith illustrated some of these on slides - Fokus housing in Sweden which was not fully independent despite varying degrees of self management, and housing associations and local authority schemes, such as Friendship House, Poole, the John Groom's flats in Finsbury Park and the

Greater London Council/Cheshire Homes scheme in Tulse Hill. The slides included examples of special housing for the disabled, a number of special units incorporated in a wider housing project for the able bodied, warden and care support schemes, communal facilities and attached residential facilities for the disabled. The main lessons which seemed to come out of these various projects was that supportive and communal facilities were under used and that mixed sheltered housing and residential care schemes did not work because of the different orientations of the two groups of residents.

Hospital long stay units for the younger physically disabled had been provided since 1960 but this was a very expensive approach and not in great demand. The degree of handicap on its own did not appear to be a very good indicator of the need for services, and once people who had been in residential care got used to living in the community, they needed much less care support than had been estimated while they were in the hospital or home. Mr Goldsmith illustrated this with slides of three couples in which both partners were severely handicapped, yet were living completely independently in the community with minimal support. Some had moved on from sheltered housing, all were well involved in their local communities, and all illustrated the importance of not under-estimating the potential for even severely handicapped people to manage on their own.

THE ROLE OF GENERAL HOUSING ASSOCIATIONS

This theme was taken up by the next speaker, Mary Goudie, Special Projects Officer, Brent People's Housing Association, who described the adaptation of ground floor flats in Victorian and Edwardian houses in inner North West London, to suit the needs of individual families with a handicapped member. The disabled were not isolated in special housing schemes but provided with a suitable conversion and an introduction to their able bodied neighbours who often then provided considerable support.

Once a disabled person had been referred to the Association, advice was sought from specialists such as the occupational therapist in the social service department, and the Centre on Environment for the Handicapped, as well as the person themselves to make a suitable conversion. Extre DOE funding was available to the Association for the capital costs involved but rents were not affected. Housing assistants were available to visit the disabled people or their families and to help them make the adjustment to their own home. The general housing association appeared to be a very successful option in enabling the handicapped to live independent lives in the community.

SPECIALIST HOUSING ASSOCIATION PROVISION

Charles Moore, Director, John Groom's Housing Association for the Disabled described an option which provided more support for the disabled person moving out from residential care, and often acted as a stepping stone to the completely independent existence described by Mr Goldsmith and Ms Goudie. The aim of the John Groom's Association was to create small communities, integrated by their design and management into normal housing areas, where wheelchair users and other disabled people could achieve their full potential and demonstrate that disability need not be a bar to a full and active life. The provision was restricted to people confined to wheelchairs and their families,but not confined to any specific handicap or disease. Its greatest advantage was to people who wanted to come out of hospital or institution.

The first scheme in Finsbury Park with 13 (now 14) flats had been opened in 1973 and provided considerable support and education in independent living to people coming out of institutions. It had been a lavish scheme with two large lifts and had provided much useful information about the needs of this group of young disabled people. They did not wish to use communal facilities; their reliance on the resident warden diminished rapidly over the first year; they did need education in basic skills such as cooking, washing, etc that were undertaken by domestic staff in most residential care situations, and many were ready to move on to more independent living after a few years. The Association's next development, Whitby Court, had no alarm system or warden and as residents moved on including some with very considerable physical disabilities, there were places in the first scheme for new people moving out of institutional care.

John Groom's Association was prepared to help with the development of local housing schemes for the disabled in any part of the country where there was a group interested to support and manage such a scheme. The Association would also welcome legislation requiring local authorities to give priority to the rehousing of the able bodied spouse, or other members of the family, if the disabled person died while in sheltered housing, so that the purpose built flat could be made available to someone else in need of the facilities.

THE CROSSROADS CARE ATTENDANT SCHEME

Support to families with a disabled member living in their own home is provided in a number of parts of the country by the Crossroads care attendant scheme. The work of this charity, whose declared aim is 'the relief of suffering', was described by its development officer Mr Richard Ambury. The care attendants, who might visit a person several times daily while their family are at work, or only monthly or even six-weekly to permit an occasional 'night off', were there to enable the relatives to carry on caring. The service might be provided in a planned way or in a crisis situation such as when a spouse fell ill, and the care attendant could move in to avoid the need for an emergency hospital admission. The scheme operated in what Dr Tait had said was erroneously called 'no man's land' and which was in reality 'everybody's field', and it supplemented rather than took over the role of the statutory bodies.

There were now 17 Crossroads schemes , two in Scotland and 15 in England from the north east to the south east. Many schemes were supported by joint finance and in some cases it had been agreed that at the end of the pilot period they would be jointly funded by both the health authority and social services. The statistics[3] on nine schemes operating from 1st April 1978 to 31st March 1979 showed that help had been given to 228 families containing 333 disabled people, and involved 24,000 hours of care, more than half of which was provided at evenings, weekends and bank holidays. This indicated the extent to which the scheme supplemented the statutory services. Anybody could make a referral to the local coordinator, but at present the Constitution of the charity did not permit it to help a disabled person living alone without family support. There had been no general problem in recruiting care attendants, although this varied somewhat from area to area.

HOSPITAL BASED SHARED CARE

An active approach to hospital provision was described by Dr Owen Smith, consultant in rheumatology and rehabilitation and medical director, Donald Wilson House, St Richard's Hospital, Chichester. A purpose built unit for the younger physically disabled had been modified to replace 6 beds with occupational, speech and physiotherapy, treatment and day care facilities and operated on a five day basis to provide assessment and active rehabilitation. This meant that over the two and a quarter years since the unit had been operational they had treated 150 patients, rather than the 22 it was planned for, and had enabled about 90% to return home. The five day system not only helped to maintain home ties and prevent institutionalisation but also gave families a role in the care of the disabled person. A multidisciplinary team including medical, nursing, therapy and social work staff were involved in assessment and consideration of options and the programme of active rehabilitation meant that most disabled people could be maintained at home indefinitely.

After two years the major category of referrals had proved to be people disabled by cardiovascular accidents (31%) followed by multiple sclerosis (21%) rheumatoid arthritis (8%) head injury (5%) motor neurone disease (4%) and other progressive conditions (20%). There had been a mortality rate of 11% during this period. Twenty per cent of patients were admitted direct from the district general hospital and although some needed to be readmitted to a general hospital ward for the first one or two weekends the majority were going home much sooner than would otherwise have been the case. After assessment and treatment only a small number of patients needed longer term hospital or terminal care and were admitted to general hospital beds. A further small number needed residential care and the social worker in the unit was invaluable in finding these people a home such as a Cheshire Home or the Royal Hospital and Home for Incurables. The unit was also able to take patients back in an emergency or for short term support and played a major educational and coordinating role in the care and rehabilitation of the young chronic sick and disabled in the locality. On all these grounds Dr Owen Smith was confident that the unit was proving extremely cost efficient, however he cautioned that more experience was needed of the role his unit was fulfilling in the delivery of care to the younger chronic sick.

RESIDENTIAL CARE SERVICES

Mrs V McMenemy, Nottinghamshire Department of Social Services, pointed out that residential homes run by social services departments were both hard to get in to and hard to get out of. There was a very real need to examine how resources were used, and how they could be used more effectively. Residential care should be aimed at people whose capacity was so restricted by disability or change in their family circumstances that they had no alternative. In practice this usually meant people who were middle aged and had a deteriorating condition or severe neurological damage. Variety within residential accommodation could be achieved by the balance between long term care and short term places for holiday, crisis and regular planned use. This latter could be a major element in the options available to families caring for a disabled member.

The philosophies in residential care varied from the total takeover in which everything was done for the resident as quickly as possible, to the hotel type which provided services without giving a resident personal responsibility or the type which encouraged personal achievement within a framework adapted to the convenience of all residents. Such a home aimed to generate family feeling, affection, responsibility and a sharing of concerns and experiences among residents. It was only this sort of home, where more than physical needs were met and residents encouraged to be more capable and responsible for their own lives that could create the motivation for them to move on to a greater degree of independence. Such an approach could improve the image of residential care and the opportunities it could offer and homes should not be seen as a last resort but rather as part of the continuum of care for the younger physically disabled.

A CAUTIONARY NOTE

The morning session ended with a cautionary note from one participant who warned against an over concentration on success stories. Success, measured in terms of the achievement of independent life in the community, was only possible for the well motivated person of normal mental intelligence. The major problem that faced the caring services was of stroke or breakdown in late middle age or congenital handicap like spasticity or spina bifida which often resulted in both mental and physical incapacity. Such people were both socially and mentally disadvantaged and unable to achieve independence in the community. They were equally in need of positive, motivating care, but success had to be measured in more modest terms than independent life in the community.

LOCAL IDENTIFICATION

In group discussion participants began by considering what could be done to improve the identification process at local level. A distinction was made between the identification of the extent of disability among those of working age in an area for policy and planning purposes, and a second voluntary stage of registration of individual handicapped people for the delivery of services. This identification process could be almost complete if it involved health visitors, general practitioners, hospitals, social services and early sources such as the birth register and the children's handicap register. The information could be used to plan services, which then had to be well publicised so that the handicapped people themselves came forward to take advantage of them.

A LOCAL FOCUS

Many participants pointed to the need for a local focus for services for the physically disabled - a source of information and a base for the coordination of services. This might be based on a unit or facility such as Donald Wilson House, involve a District disability team that takes over from the children's handicap teams advocated in the Court report, or one or more specialists within the social services or health fields; for example a health visitor with special responsibility for the disabled in all or part of a health district. Whatever the focus, it had to fully involve all statutory and voluntary bodies operating in the District, and as well as providing services and information about services, it had to be sensitive and supportive to the ideas coming from the handicapped themselves.

JOINT PLANNING

Where there was a focus or team there could be integrated planning of services to back up joint planning at officer level - for example in the joint care planning teams run by health and social services departments. It was a team such as the JCPT who could look at the resources that were already being allocated to the younger physically disabled, look at whether or not these resources were being properly used and recommend new developments that might be joint financed or jointly funded. Several participants warned the DHSS of the problems being faced by joint finance programmes, which had been so successful at pump priming that they had now pre-empted all growth in social services department programmes. The rules for the use of this money would have to be modified if it was to continue to support the ideas arising out of joint planning.

Attention was drawn to the role of voluntary organisations in joint planning and the provision of services. In many areas they were providing services on behalf of statutory authorities using joint finance monies. A local conference might be necessary to start the identification and planning process and to get all local voluntary groups involved.

ASSESSMENT AND PROVISION

Participants stressed that the identification process should be followed not only by a local focus and joint planning of services, but also by an accurate assessment of individual needs. A hospital unit like Donald Wilson House could be useful, but even without such a facility the multi-disciplinary District disability team could play an important role in the assessment of individuals and in communication and the provision of information about services. The problem of the younger physically disabled was one of dependency rather than disability and assessment was essential to indicate the extent to which independence was restricted, the action that could be taken to reduce this and the best approach to each person's social, medical, housing, care, educational, employment,cultural and other needs.

Assessment could not be a once for all activity. Dependency was not a static situation; some handicapped people could become more independent, others with a progressive condition were likely to become less independent. Continuous, updated information on the needs of the disabled group within a district could be maintained by the team or by a designated individual, known to all organisations such as a health visitor or social worker. Where handicapped people had the potential to become more independent, NHS and residential home care staff had a vital role in motivating residents to move on or to achieve the maximum of which they were capable. The definition of success varied, but a positive approach backed up by a wide range of local options was the key to the individual disabled person being able to lead a full and satisfying life.

Shirley J Hardy
30th June 1979

REFERENCES

1 Special Education Needs - report of the Committee of Enquiry into the Education of Handicapped Children and Young People. HMSO 1978 Chairman - Mrs H M Warnock

2 Handicapped and Impaired in Great Britain - Amelia Harris Office of Population Censuses and Surveys HMSO 1971

3 Crossroads Schemes national statistics April 1978 - 1979. obtainable from Crossroads Care Attendant Scheme Trust, 11 Whitehall Road, Rugby, Warwickshire.